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The Experience of Hope Among Women With HIV/AIDS: Themes on Light

By

Carol Jeanne Vogler

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of **DOCTOR OF PHILOSOPHY**

DEPARTMENT OF HUMAN ECOLOGY

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Carol J. Vogler

18943 82 Avenue
Edmonton, Alberta
T5T5C6

Date 29 August, 2001

UNIVERSITY OF ALBERTA

FACULTY OF GRADUATE STUDIES AND RESEARCH

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled THE EXPERIENCE OF HOPE AMONG WOMEN WITH HIV/AIDS: THEMES ON LIGHT submitted by Carol Jeanne Vogler in partial fulfillment of the requirements of the degree of DOCTOR OF PHILOSOPHY.

Dianne K. Kieren

Dr. Dianne K. Kieren, Co-Supervisor

N. Keating

Dr. Norah C. Keating, Co-Supervisor

Ronna Jayne

Dr. Ronna Fay Jevne

Jeanette Boman

Dr. Jeanette Boman

Kaye A. Herth

Dr. Kaye A. Herth, External Examiner

Date: May 8, 2001

To my Dad –

Whose intelligence, love, wit, hugs, and playful approach to life made him a unique man and a remarkable father. As a physician dedicated to family practice, he personified the perfect blend of science, art, intuition, faith, humour, and love. Degrees notwithstanding, in my heart there will only ever be one 'Dr. Vogler'...

A Walk

My eyes already touch the sunny hill,
going far ahead of the road I have begun.
So we are grasped by what we cannot grasp;
it has its inner light, even from a distance –

and changes us, even if we do not reach it,
into something else, which, hardly sensing it, we already are;
a gesture waves us on, answering our own wave...
but what we feel is the wind in our faces.

(R.. M. Rilke, 1924)

ABSTRACT

While the word hope is used casually in everyday speech, the experience of hope can be deeply felt, particularly in times of illness, strife, suffering or personal challenge. For hundreds of thousands of people in the United States, HIV/AIDS presents a exceedingly complex situation of physical suffering, emotional intensity, and stress. With the advent of protease inhibitors in 1995, people with HIV are living longer, and with greater health than ever before. Nevertheless, AIDS continues to be a leading cause of death among Americans, particularly among women. The fact that currently there is neither a vaccine for HIV nor a cure for AIDS and notable increases in HIV infection are being seen among selected constituencies of people (Hispanic and African American women and men and young homosexual men) presents cause for continued concern.

Despite the burgeoning literature related to hope, few studies have investigated the lived-experience of hope among people with HIV/AIDS. Using a hermeneutic phenomenological approach, this investigation explores the experience of hope among five women who live with HIV/AIDS. Embracing significant assumptions from both feminism and human ecology, a hermeneutic phenomenological approach is used based upon van Manen's (1994) six methodological guidelines. Personal reflections on the history of the AIDS epidemic in the United States contextualize this study revealing, in part, the perspective and biases of the researcher and supporting the need for this particular research endeavor.

Through the use of photography, participant journals, and a series of conversations each woman's personal experience of hope is illuminated. The women's

descriptions of hope reveal several common threads woven through each of their experiences. These common threads are revealed and interpreted as: *Hope: In the Company of Hopelessness; Hope: Moving Toward the Light; Hope: An Inner-Outer Light; Hope: The Impossible Possibility of Light; and Hope: A Present Light*. Insights into the meaning and experience of hope are discussed while suggestions are offered for further explorations of hope among women living with HIV/AIDS.

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A work such as this represents a wide circle of colleagues, friends, family, and loved ones who enriched the research process and nurtured my hope. Therefore I acknowledge with gratitude…

All those living with HIV/AIDS and those who are no longer with us; especially those who dared to stand up, come out, organize, and love in the midst of devastation and hatred. The world is a better place and we are wiser because of you.

My participants – five women who touched my heart and life with their hope and their witness. I carry your story, I know your real names, and I will never forget you!

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CHAPTER ONE

HOPE UNFOLDS

Hope is a simple word. Used casually and frequently in everyday conversation, we can hope for good weather, hope to arrive somewhere on time, or hope to win the lottery. At the same time, hope is a word that can hold profound meaning. When faced with challenges such as illness, injustice or tragedy, we turn to hope. Many have 'beaten the odds' in times of adversity or affliction, attributing their victory solely to the sustaining power of hope. Similarly, the phrase 'there is no hope' is tantamount to announcing death itself. We feel the presence of hope and we feel acutely its absence. What then, is the meaning of this unpretentious word?

In fact, literature about hope is plentiful. Researchers have explored the dimensions and character of hope. Philosophers have pondered hope. Theologians have affirmed hope as both a future assurance and a present reality. Poets have glorified and cursed hope. More recently, conceptualizations and measurements of individual hope have contributed to an understanding of hope as important for health and well-being. It appears that research has confirmed what perhaps has been known all along: hope is commonly felt as a deeply meaningful dimension of human experience. Nevertheless, hope remains an elusive concept – real, but intangible; positive, but hard to grasp; felt, but difficult to describe; necessary, but not always easily accessed.

The question guiding this research is: *what is the experience of hope among women with HIV/AIDS?* To many, the pairing of the words "AIDS" and "hope" would be considered an oxymoron. According to 1999 figures from the United States Centers for Disease Control and Prevention (commonly known as the CDC), an estimated one in 250 Americans are living with the Human Immunodeficiency Virus (HIV), or approximately 1 in 100 men and 1 in 600 women. Acquired Immunodeficiency Syndrome (AIDS) has already claimed the lives of hundreds of thousands of men, women and children in the United States and millions worldwide (Centers for Disease Control [CDC], 1999). In the early years, AIDS deaths mounted exponentially, nearly

doubling each year between 1980 and 1990. In 1981, just 31 deaths had been attributed to AIDS. Those 31 deaths stand in sharp contrast to the nearly 13,000 AIDS deaths just four years later (CDC, 1999). By 1985 new cases of AIDS were being tallied at a rate of about 1,000 *per month* (Shilts, 1988). Common among AIDS activists in the early years was the following slogan: AIDS = death.

In the United States, more deaths are attributed to AIDS than the combined casualties from the Korean War, the Gulf War and the Vietnam War (Lather & Smithies, 1997). AIDS continues to take its toll as the second leading cause of death among American adults between the ages of twenty-five and forty-four, second only to cardiovascular disease (CDC, 2000). As we begin the second millennium, AIDS remains a global pandemic affecting millions worldwide. Moreover, since the early part of the 1990's, fifty percent of those infected are women (Auer, 1996). Statistical realities of AIDS alone prompt the question: *where is hope?*

Throughout the course of this project many people have asked me why I have focused on hope and HIV/AIDS. Why not explore hope among other life-threatening chronic illnesses, they ask? I often wondered if the same question would be asked of other researchers, whose studies took place among specific populations such as women with breast cancer or people with leukemia. I have wondered whether their questions reflected homophobia, the stigma still attached to HIV/AIDS, a lack of understanding concerning the scope of the epidemic or disinterest in the issues at heart of – and particular to – HIV/AIDS. Likewise, I have wondered whether people really believe HIV is no longer an important issue?

Although it parallels other conditions (including some cancers), HIV disease is unique in a number of significant aspects. First, the median age of those infected is younger than those suffering from any other illness. Unlike cancer, marginalized populations are disproportionally affected with HIV/AIDS and the survival/cure rate for all kinds of cancers far surpasses the survival/cure rate associated with HIV/AIDS. Moreover, HIV/AIDS carries social stigma in a

way that cancer does not. Finally, HIV/AIDS is preventable. These are important distinctions influencing the experience of hope and reactions to a diagnosis of HIV infection.

AIDS was first recognized in the United States in the early 1980's. Since then tremendous advances have been made in the areas of HIV prevention and treatment as well as in increased awareness and compassion towards those affected by HIV/AIDS. Currently there are signs of promise in combating HIV and staving off AIDS. During the last fifteen years, an assortment of drugs became widely available – some of the drugs combat HIV while others serve as prophylaxes to the opportunistic infections associated with AIDS. Today, more people are living longer with HIV infection, and with greater health than ever before. That is good news, and a sign of hope to many. The ongoing realities of the epidemic, however, demonstrate that HIV is not yet under control.

While recent statistics show declining trends in AIDS diagnoses and deaths, rates of HIV infection have remained steady. Moreover, there is some evidence that HIV infection is actually increasing among certain populations; with most new diagnoses occurring among young people, women and minorities (CDC, 1999). There is currently no vaccine to prevent HIV infection and no cure for AIDS. Consequently, for years to come, AIDS deaths will continue to mount in the United States and around the world.

In Chapter One the groundwork is laid for this study. Through a personal/historical overview of the epidemic as it has unfolded in the United States and by highlighting particular issues corresponding to each time period or trend, the rationale for the emphasis on hope in the midst of HIV/ AIDS is offered.

The Question

In 1997, I contacted the AIDS Services Center (ASC) to inquire about conducting research on hope with ASC clients. I had earlier worked at ASC as a case manager for women with HIV/AIDS and when I contacted the agency it had been less than two years since my

departure. One of the first people I spoke with was a colleague with whom I had worked. When I told her my plans, she hesitated and then exclaimed, *"You know Carol, times have really changed since you've been here. These days it feels as if there is hope... people are really responding to those new drugs."* My colleague was referring to protease inhibitors, a new class of HIV drugs, which were first introduced in 1995, the year I left the agency. Since then, there has been some indication that AIDS deaths have reached a plateau and the number of newly diagnosed AIDS cases has dwindled considerably. Many attribute these declines to the advent and use of protease inhibitors. My colleague's response intrigued me. It reflects the belief that hope is only necessary in times of trouble, becoming mundane and uninteresting when out of the crisis mode.

In the spring of 1995, my friend Danny died from AIDS-related complications. Among his last words was this pronouncement: *"Now, there is no hope."* In the contrast between my co-worker's comment, *These days it feels like there is hope* and my friend Danny's deathbed utterance, is captured one of the most characteristic themes of the epidemic: the linkage of hope with a cure for HIV/AIDS. The two comments reflect this understanding of hope. For Danny, once death was immanent, hope was gone. He had lost his race with time; his own cure would not come. On the other hand, the affirmation of the presence of hope was pronounced by an ASC case manager *only* because of the success of the new protease inhibitors in prolonging life, implying that hope was not present earlier in the epidemic.

The first decade of HIV/AIDS in the U.S. was truly frightful and sorrowful, but hope was not absent. Even as people were dying and HIV appeared uncontrollable, I *experienced* hope—linked neither with a cure nor miracle drug. Witnessing of hope *enacted* in the actions of people, and *embodied* in the affirmation of spiritual and emotional life even while facing the probability of physical death facilitated my own experience of hope. This strengthened my conviction that "hope as cure" is a narrow boundary for the invisible and mysterious force called hope.

While working with the women's program at ASC I felt with certainty the experience of hope—witnessing it in others and experiencing it myself. The question at the heart of this exploration is rooted in my earlier experiences of hope in the context of HIV/AIDS. What is the experience of hope in the midst of HIV/AIDS? Paralleling this is the corresponding question what does hope mean to those who daily live with HIV/AIDS?

This study explores the experience of hope among a select group of HIV-positive women (meaning each is infected with the virus that causes AIDS). The women live in the same geographical area of the United States. Through a series of conversations with each of the women, a hermeneutic phenomenological approach was utilized to explore each woman's lived experience of hope in the context of HIV/AIDS. As a hermeneutic phenomenological exploration, the research question guiding this study has dual components: what is hope *like* (and) what does hope *mean* for each of the participating women?

Overview of the Chapters

In Chapter One of this dissertation two parallel subjects are woven together: the history of HIV/AIDS in the United States and personal remembrances of individuals with HIV/AIDS whom I have known. Chapter One, then, positions this study within the unfolding dynamics of the HIV/AIDS epidemic by providing the personal-historical context of this study and my involvement with AIDS and hope. In Chapter Two I provide an overview of the literature, situating this study among selected research in the dual areas of hope and HIV/AIDS. The theoretical foundations of the study are outlined in Chapter Three as I highlight important concepts from Human Ecology, Feminism and Hermeneutic Phenomenology. A description of the methodological challenges embedded within this study and the procedures used to guide the research process are offered in Chapter Four. Together, Chapters Five and Six comprise the hermeneutic phenomenological exploration. First, in Chapter Five, I describe each of the participants' experiences of hope while in Chapter Six, I explore the meaning of hope by

reflecting upon salient themes, or threads woven through the individual descriptions. Chapter Seven, then, is the concluding chapter in which I consider the personal significance of this study and its significance in relation to the hope literature. This is done 'in conversation with' a quilt, which was produced as part of this project.

Much has been written about the socio-political and biological realities of HIV/AIDS. Likewise, much has been written about the topic of hope. Interestingly, research about hope among HIV positive individuals is limited and explorations of hope among women with HIV/AIDS even more sparse. By pairing hope and HIV/AIDS, and by delimiting the sample to women, this dissertation is unique in both scope and intent.

My ethical obligation to the participants and my responsibility to the field of hermeneutic phenomenology are to provide accurate descriptions and insightful representations of the meaning of hope. It is my hope that as a reader of this thesis, you will not only come to understand the meaning of hope for the women who participated in this study, but also that you will be brought into dialogue with what hope means to you personally. If this occurs, then together we will move toward what Gadamer (1989) termed a "fusion of horizons": a moment in time where differing vantagepoints merge in mutual understanding. In this case, may our differing vantagepoints merge in mutual understanding about the meaning of hope.

Faces And Phases

This study explores the experience of hope among women who live with HIV infection and AIDS. The word AIDS defines a combination of medical conditions, specifically the presence of HIV (Human Immunodeficiency Virus) and either one or more opportunistic infections from the CDC's classification list or a T-cell count below 200. The word AIDS is also laden with meaning, inherited from its initial linkage with homosexuality and drug use, its terminal realities, and the uncertainties of its related illnesses. Women's experiences of HIV/AIDS cannot be lifted from the sociopolitical context within which the epidemic has been defined. Responses to

diagnoses, the way individuals have (and have not) incorporated HIV into their lives, and the continued concerns for secrecy about their illnesses all are common particularities of living with HIV/AIDS. An underlying assumption of this project is that hope is seeded by one's context and emerges within particular situations: hope happens in the context of everyday existence. For the participants in this research, then, hope is experienced in the context of HIV/AIDS, a reality that has permeated not only the lives of the participants, but the whole of U.S. society.

In order to better understand the context within which the participants experience hope, and some of my pre-understandings upon beginning this research, the following pages describe five phases of the HIV/AIDS epidemic as it progressed in the United States over a twenty year time span. The phases offer insight into the characteristics of the unfolding epidemic, which have contributed to the current trends and issues related to women and HIV/AIDS. The breakdown into phases corresponds to certain epidemiological trends emerging during the past twenty years, but unquestionably reflects a subjective portrayal of the unfolding epidemic.

My personal involvement with HIV/AIDS has in some ways paralleled the sociopolitical and historical changes in the epidemic, and brought me to an interest in personal experiences of hope. From an early awareness of AIDS-related injustice to later full-time involvement with people affected by HIV/AIDS, HIV/AIDS has been a significant thread woven through the past fifteen years of my life. Upon reflection, I realize too how interwoven the experience of hope has been in the midst of the epidemic. As I describe the five phases of HIV/AIDS in the United States, I have assigned each phase a 'face'—individuals who I remember and whose life represents for me a turning point or characteristic phase of the unfolding epidemic. Each of the phases/faces also represents one of five words, which for me have come to characterize the AIDS epidemic in the U.S.: uncertainty; anger; love; sorrow; hope.

Phase One: The Early Years of AIDS, 1980-1985

"Patrick"

Boston, Massachusetts was an exciting place to spend three years of my seminary training. In comparison to the small town of Bethlehem Pennsylvania (where I was raised and later returned to complete my studies for ministry within the Moravian Church), the school of Theology at Boston University during the early 1980's offered more than I could have imagined. There I was introduced to cultures, people and modes of thought vastly different from any I had encountered before. Instead of spawning personal conflict, I found much of what greeted me in Boston to be deeply congruent with my heart's leading. It is Boston to which I can trace the roots of my alignment with Christian social justice, feminism, and AIDS activism.

Among my classmates I remember in particular one older student who was in his last year of seminary training whose name was 'Patrick'. We were assigned as study partners and soon a friendship developed between us. An impassioned but quiet man, Patrick was the first openly gay person I had ever met. At forty-three, Patrick had spent most of his life fighting and repressing his homosexuality. He grew up in New England, but moving to Boston was freeing for Patrick because he could "be himself" for the first time. Although he wanted to settle down to a quieter life, Patrick found the gay scene exciting: dancing at the discos and gay bars till all hours, dating an endless number of men, and having sex…*lots* of sex. Patrick had even gone to New York a few times to enjoy the excitement of that city's gay scene.

Patrick's newly discovered freedom with himself and his sexuality, while cause for great personal joy, also generated personal conflict. Patrick felt called to the ministry and wanted desperately to be ordained and serve as Pastor of a church. Patrick knew however, that the possibility of a church vocation was impossible if he was openly gay. Along with this, Patrick was convinced that his parents and siblings would disown him if they ever discovered his homosexuality. Consequently, Patrick never shared this dimension of himself with his family.

Neither Patrick nor the rest of us would have the chance to see his personal conflicts

resolved. Before the end of the spring term, Patrick suddenly became seriously ill and was hospitalized for what appeared to be an extreme case of the flu. Soon he developed pneumonia. Next came the diagnosis of "some sort of cancer" but the physicians were perplexed about the rapid deterioration of Patrick's condition. On more than one occasion Patrick heard exclaimed, "[we've] never seen anything like this!" In a matter of weeks, a seemingly healthy man had entered an uncontrollable spiral of physical decline.

I visited Patrick only twice. The first time he was well enough to talk to me and, although he was worried about the possibility of cancer, he seemed to think he'd be able to finish the term and graduate. When I visited him just a week later an oxygen mask covered Patrick's face and his breathing was shallow; he was so weak he couldn't speak. Worried, but certain I'd see him again soon, I sat with him for awhile, said good-bye and left the room. Just a few days following my second visit, Patrick died, alone in the tiny hospital in his hometown. Reflecting on his death just a few years later I realized that, although undiagnosed at the time, Patrick quite probably died from AIDS.

Uncertainty

Phase One of HIV/AIDS represents the early years of HIV among gay men in the United States. The late seventies had marked a time of sexual freedom and openness in the United States as the gay liberation movement was underway. Building on the foundations of the African-American Civil Rights and women's movements in the United States, and galvanized by the Stonewall Riots of 1969[1], gay men had created a culture wherein sexuality was celebrated and community was nurtured. Bath houses, and other places where men could go to have multiple (and anonymous) sexual encounters, were popular in large urban centers such as New York, Boston, and San Francisco. These places were also breeding grounds for every type of sexually

[1]Riots sparked by a June, 1969 raid on a New York City gay bar (The Stonewall) have come to represent the struggle for gay rights, as this was the first time on record that homosexual patrons had fought back.

transmitted disease (Burkett, 1995; Shilts, 1988).

On June 5, 1981, the CDC reported five cases of a rare pneumonia among young gay men in Los Angeles. One month later, in July of 1981 the *New York Times* ran an article which headlined: "Rare Cancer Seen in Forty One Homosexuals" (Altman, 1981). Although garnering little attention at the time, the appearance of this article marks the delineation of the time *before* and *after* AIDS. Nonchalance soon gave way to widespread confusion and fear. Physicians and scientists were puzzled by what they saw: seemingly healthy young men were being assaulted by a variety of debilitating opportunistic infections which a healthy immune system typically combats. The only common denominator of the strange new disease seemed to be that it was affecting gay men. As the number of cases increased—particularly in New York City and San Francisco, it rapidly and vividly became apparent that the medical establishment was now dealing with a deadly, infectious disease that decimated the immune system. Moreover, there seemed to be no way to stop it. Even though the CDC and *The New England Journal of Medicine* had reported heterosexual IV drug users with the new syndrome, its association with gay men led to the original designation of the condition as GRID, meaning "Gay Related Immune Deficiency" (Oppenheimer, 1992; Shilts, 1988).

The appearance of the unusual infectious disease added fuel to the fire of the "Religious Right", a conservative political movement which was gaining momentum in the United States during the early 1980's. Charismatic speakers like Jerry Falwell of the Moral Majority and Pat Buchanan spoke openly about GRID calling it the 'Gay Plague' and proclaiming it to be God's wrath against homosexuals, "proof" of a "deviant lifestyle" (Rushing, 1995; Shilts, 1988; Sontag, 1988). Even later, when AIDS was affirmed to be the result of a blood-borne pathogen, a virus, The American Council of Churches declared that HIV-AIDS was God's judgment against male homosexuals. These voices tapped into public fear regarding the infectious virus and mainstream

America's apprehension and lack of knowledge regarding homosexuality. The virulence of the disease and the moral injunctions against gay men created public hysteria in response to HIV/AIDS the results of which were panic about AIDS-contagion and actions of prejudice and increased violence toward gay men (Fumento, 1990; Zuckerman, 1988).

The fact that HIV was a bloodborne rather than airborne pathogen was not adequately conveyed through the media. Fear of contagion through casual contact, such as kissing or sharing public facilities, led to what can only be called AIDS hysteria. Police, emergency response teams and firefighters were trained in the special handling of persons with AIDS, including the use of protective clothing rubber gloves and facemasks. Many people with AIDS (and often those *suspected* of having AIDS) lost their jobs and apartments; while many others were refused treatment by dentists and physicians, or refused services in restaurants, banks, and hair salons. Funeral homes refused assistance to those who had died from AIDS. Ambulance drivers were told to "drive slowly" when responding to a known AIDS-related call, increasing the likelihood that the person would be dead before the ambulance arrived. Moreover, many people were abandoned by their friends and family due to the fears and myths surrounding AIDS and its link with homosexuality (Fee & Fox, 1992; Rushing, 1995; Shilts, 1988; Wallis, 1985).

During Phase One, the 'face' of HIV/AIDS in the United States was that of young gay men, similar to "Patrick". Social and religious disdain for homosexuals and AIDS meant that countless numbers of men died alone, estranged from their families and communities of faith. These men faced assaults from every sphere of society while fighting for bodily survival, and living in fear of certain, and an oftentimes horrendous, death. AIDS was cutting a swath in the gay communities; men in the prime of their life were dying while American society seemed to turn a blind eye.

I remember those years, but with a sense of disbelief. In 1984 a seminary professor in Bethlehem chastised me for writing a paper entitled *Pastoral Care of Those With AIDS*, saying

the topic was inappropriate. Many pastors and other Christians who disagreed with the pronouncements of hatred coming from the so-called Moral Majority remained silent for fear of themselves being accused of being gay. Science was at a loss to understand and effectively deal with the new virus called HIV. In the midst of the hysteria, an undercurrent was swelling to a tidal wave as HIV infection was already manifesting in every sector of American society.

The word associated with Phase One of AIDS in the United States is "uncertainty". Medical science was uncertain about the realities of the new epidemic. Policy makers were uncertain about the extent of government involvement. Mainstream churches were uncertain about how to deal with homosexuality and therefore became paralyzed, unable to help individuals and families. There had already been uncertainty about death and sexuality issues in American Society; AIDS brought these to the fore and exacerbated the uncertainty. Among sexually active gay men there was uncertainty about who to believe and what *was* or *wasn't* safe sexual behaviour. Among families and friends of those who were suffering from AIDS there was uncertainty about how to respond. AIDS was mysterious and demoralizing. The injustice, suffering and grief were overwhelming. It was a time of uncertainty and I often asked myself, where is hope?

Phase Two: An Epidemic of the Marginalized

"Deborah"

Just a few years after Patrick's death I had returned to Pennsylvania and was working with a childrens program in one of Bethlehem's subsidized housing projects. One child who entered the summer program that year immediately stole my heart. Nikki was sprightly and eager to learn; both a child's sparkle and adult pain shone from her eyes. I soon learned that Nikki's mother, Deborah, had recently been diagnosed with cervical cancer.

Deborah, an African American woman not quite thirty years old, had been a long time injection drug user who shared needles as freely as she shared her body. During my first home

visit, I witnessed Nikki ease her screaming mother's pain by giving her a morphine injection—the little girl's hands working the syringe as masterfully as any nurse. After her mother was calmed, Nikki emptied the commode chair and began to cook a Kraft dinner for herself and her three-year-old sister. That was July of 1986. I later discovered that same day happened also to be Nikki's twelfth birthday.

Soon, I had gotten to know Deborah and quite appreciated her quick wit and "no bull shit" attitude. Once, while driving Deborah to a medical appointment, I haphazardly told her she looked pretty good that day. She looked at me askance and quipped, *"Yeah, right! When you're as sick as I am and somebody says 'you look good' they really mean you look like hell."* As usual, she had seen through my lie, however well intentioned! Deborah loved her daughters dearly but was simply too ill to take care of them. On more than one occasion Deborah expressed her sorrow over losing quality time with her children due to her addictions.

In late August, the two girls were living with me while Deborah's sister, a registered nurse, was caring for her in a neighboring town. In mid-September without warning Deborah died, less than four months after her cancer diagnosis. I can still hear Nikki's piercing screams after being told of her mother's death. Deborah's age at the onset of her cancer, her history of needle use and multiple sexual partners, the virulence of her cancer and rapidity of her death were indicative of HIV/AIDS. Although, like Patrick, Deborah was never diagnosed, I thought then, and am convinced now that her death was AIDS-related.

Anger

Deborah represents Phase Two of HIV/AIDS in the United States, a phase that overlaps and expands on Phase One: AIDS among non-gay populations. In 1983 the acronym "AIDS" (Acquired Immune Deficiency Syndrome) replaced the original term "GRID" (Gay Related Immunodeficiency) to more accurately reflect the true nature of the virus, HIV (Goldstein, 1997; Grmek, 1990; Shilts, 1988). Viruses do not attack specific groups of people; HIV is a bloodborne

virus, spread via specific behaviors, which simply cannot be relegated to one social group. The change in name from GRID to AIDS marked a fundamental shift in recognition of the realities of the Human Immunodeficiency Virus and the epidemic.

Because HIV is a bloodborne pathogen, it is known to be found in certain bodily fluids (primarily blood, semen, and vaginal fluid) and passed from one individual to another through the exchange of these fluids. Once that reality became apparent in the medical and social realms, a more realistic and sobering picture of AIDS emerged. If not confined to gay men, then everyone who engaged in so-called "risky" behaviors was at risk for HIV. "Risky behaviors" included two common social realities: unprotected sex and sharing needles.

During Phase One AIDS was identified with gay men. Sadly, this not only justified discrimination against gay men and marginalized them further from society, but also engendered a false sense of security among the general (non-gay) population. Consequently, public education regarding the *behaviors* associated with HIV infection was slow in coming. Instead, the message to the public was 'if you're not gay, you're not at risk'. Doctors suspected HIV infection only when white gay males came to them with complaints. Meanwhile, the virus was going undetected among men who did not appear gay, men and women who received blood products tainted with HIV, women who were sexual partners of men who were infected and men and women who shared needles while using injection drugs (Denenberg, 1995). The CDC's transmission categories obscured cases among women:

> ...[In the CDC transmission surveillance reports] heterosexual transmission did not exist as a separate category; significantly the next highest transmission category for women after "injection drug use" was "non/unknown." At the end of 1983, 36% of female cases—compared to 4% of male cases—were in this category . . .
>
> (Campbell, 1999, p. 3)

Thus, as Gena Corea (1992) stated, "In the public silence where danger warnings to women might have sounded, women could hear the message: this is not our epidemic" (p. 17).

My own experience working with HIV positive women confirmed that women were not viewed as being at risk. Many women told me of their physician's surprise with test results and/or refusal to provide an HIV test even when prodded. During the 1980's and early 1990's, too many women heard the following comments from their physicians: "Why do *you* want an HIV test"; "You're not gay"; and, "Women don't get HIV". Women were excluded both from statistical representatives of HIV/AIDS and prevention education efforts to stop the spread of HIV.

The implications of the exclusion of women and disregard for the realities of HIV were deadly and had far reaching consequences. Lack of public education about the risks of HIV meant that women like Deborah never knew they were at risk for HIV infection. Neither did most physicians and health care workers recognize women's vulnerability. Gynecological manifestations of HIV infection (i.e. cervical cancer, chronic yeast infections and complications related to pregnancy) went unnoticed by physicians, who accepted, and perpetuated the myth that women didn't get HIV because it was a "gay disease". Moreover, the latency period from the time of infection to the onset of symptoms meant that the potential magnitude of the epidemic among women continued "largely unremarked" (Campbell, 1999).

Although Deborah was one important face among those affected by HIV/AIDS during Phase Two, other faces were embedded within. It wasn't until 1985 that in the United States the Red Cross began screening blood for HIV. Between 1978 and 1985, 30-70 percent of hemophiliacs treated with blood transfusions became infected with HIV. Moreover, 90 persent of those individuals who received contaminated blood before 1985 became infected with HIV. These figures have been dramatically reduced since blood screening came into effect. Still, many AIDS deaths could have been prevented if the Red Cross had earlier acted upon what was known

about HIV and the blood supply (Bartlett & Finkbeiner, 1997; Corea, 1992; Patton, 1994; Shilts, 1988).

Realizing that every single case of AIDS represented a circle of relationships including partners, children, family members and friends, during the late 1980's it became apparent that HIV not only *infected* some but also *affected* scores of others. Certainly there was enough knowledge about HIV during phase two of HIV/AIDS in the U.S. to warrant widespread public education. Instead of communicating the facts known about HIV and taking leadership in preventing the spread of HIV, the U.S. government's silence allowed the myths surrounding AIDS to prevail and the virus to continue to spread.

Along with the debilitating nature of HIV disease and the range of potential diseases associated with AIDS, persons living with AIDS (PWAs) in the United States during the 1980's already lived with uncertainty and fear. Gay men were being publicly and socially ostracized as they were blamed for the prevalence of HIV/AIDS. New drugs came and went—each one touted as the next miracle cure. Most of the drugs were eventually "outsmarted" by the continually mutating virus. With no cure in site, no end to HIV discrimination and the numbers increasing as HIV made its way to every corner in the nation, there was much to challenge and undermine hope.

The word characterizing Phase Two is anger. Prejudice against homosexuals legitimized the perpetuation of myths and silence regarding the dangers of HIV. The American public was angry with homosexuals for 'causing' AIDS. Gay men and others were angry at the lack of public outcry about AIDS. Consequently, AIDS activists began to fight back against the mainstream response to HIV/AIDS.

Instead of becoming powerless in the face of public hatred and governmental inertia, the anger felt by gay communities in New York, San Francisco, and other urban centers fueled mobilization in response to AIDS. Building on ties forged during earlier years of gay pride, the

infrastructure was already in place for widespread community organizing. After caring for and burying (too many) friends and lovers another gay movement began, this time one of political lobbying and social outcry. The earlier slogan "AIDS = death" gave way to the more purposeful: Silence = Death.

By the mid-1980's a movement was afoot, characterized by devastating grief and the fight for physical survival and social recognition. Beginning in the urban centers but eventually taking hold in every state of the country, AIDS support groups were formed, information hotlines were set up, volunteer caregivers (known as "buddies") were assigned to those living with AIDS, HIV prevention efforts were organized, condoms and clean needles were distributed. Advocacy and political action groups such as the AIDS Coalition To Unleash Power (ACT UP) lobbied government agencies and officials, and AIDS Service Organizations (ASOs) were established to provide legal, social and emotional support to those living with HIV and dying with AIDS. The names of two ASO's reflect the urgency of the times: the Gay Men's Health Crisis Center in New York City and The KS Foundation[2] in San Francisco were established. Throughout history there has been no social movement analogous to that which evolved in response to HIV/AIDS (Adam and Sears, 1996; Kayal, 1993; Shilts, 1988).

Along with the anger, Phase Two for me was a time of hope. Hope was present as people refused to become further victimized and regained a sense of pride and personal power. Hope was present as the connections were made between personal realities and needs and the political imperative for action. Hope was present as people worked together in response to a devastating crisis. And, hope was present in the relationships that developed in response to AIDS.

Phase Three: We Get Organized

"Danny"

The third face of AIDS is that of a dedicated, charming AIDS activist named Danny.

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[2] KS stands for Kaposis Sarcoma, an opportunistic infection associated with AIDS.

Until his death in 1995 Danny was among those who at that time were being called *long term survivors*, those who had lived past the median life expectancy after receiving an AIDS diagnosis. Danny had lived for many years first with HIV infection and then many years with an AIDS diagnosis.

In the beginning of the epidemic, the U.S. government simply did not make AIDS a high priority; consequently leadership in response to the epidemic came from the gay communities themselves (Burkett, 1995; Campbell, 1999; Corea, 1992; Herek & Greene, 1995; Shilts, 1988). The carefree days of discos, bathhouses and unprotected sex were over. Instead of partying, gay men across the country began organizing themselves in response to AIDS. The 1980's were busy years as AIDS hospices were opened and massive HIV prevention efforts took place within gay communities. AIDS activists lobbied drug companies and politicians demanding increases in funding for drug testing and treatment protocols. Public policy and human rights abuses were brought to the fore and challenged in courtrooms across the nation. In addition, gay communities began to reclaim and invent rituals of remembrance and public expressions of grief and hope.

Since his own diagnosis, Danny was among those who worked hard, caring for his friends who were sick and dying, teaching young people and gay men about safe sex, speaking publicly about AIDS and endlessly seeking more money for the fledgling AIDS Service Organization he helped to form. Danny was a tireless AIDS activist. He was a popular public speaker and was highly regarded by other AIDS services organizations (ASOs) in his area.

Effeminate and attracted to men, Danny had always felt different than other boys. When Danny was in his teens, following a counselor's advice his parents agreed to put Danny through a series of shock treatments to help cure his homosexual tendencies. *"Thank God that didn't work,"* Danny exclaimed more than once. Danny never was cured of his sexuality, having many loves—and many lovers—during his forty-five year life. His dream however, before he died, was to officially marry his partner of six years.

Danny believed strongly that a cure for AIDS was just a matter of time. He realized that his was a life-and-death race, wishing openly that often promised "scientific breakthrough" would happen before his own death. The day before Danny died was a difficult one for his loved ones. Danny spoke honestly to his partner and his mother and stepfather about his life and pending death. These were the three who had faithfully changed Danny's incontinence pads, tended to his IV bag, washed his emaciated body, prayed and laughed with him. At one point Danny offered a simple sentence, one that conveyed a profound sense of acceptance amidst utter disappointment. Danny's words were uncomplicated and soft, but carried much weight: *"Now,"* said Danny, *"there is no hope."*

In 1995, while attending Danny's funeral I was struck by the dramatic difference between this funeral and what I remembered from the early years of the epidemic. There we were, gathered in a Catholic Church in a conservative New England town, with a Catholic priest officiating, at the funeral of an openly gay man! Those assembled were a diverse group indeed: young and old, gay and straight, friends and family. The pallbearers were both women and men, each proudly wearing a red AIDS ribbon and a rainbow pin (a symbol of gay pride) which Danny's mother had given to us. Danny's partner sat with Danny's family and Danny's stepfather delivered the eulogy using the words *gay* and *AIDS* freely and proudly. He even referred to Danny as a "fabulous queen", which had been a favorite expression of Danny's in reference to himself.

Danny had helped design the panel that would bear his name and he added to the tens of thousands of similar individual panels comprising the AIDS quilt[3]. When Danny's panel was unveiled, I was overcome again with deep sadness over the loss of this whimsical, gifted, and gentle man. I recognized the loss to society of so many young talented people, who carried so much potential. I thought too of Patrick and Deborah and scores of others like them; those, unlike

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[3] The AIDS Memorial Quilt is described on page 21 of this chapter.

Danny, whose deaths were secret, whose loves were closeted, whose illnesses progressed undiagnosed and uncounted.

Love

During the later half of the 1980's AIDS gained public recognition, even if still not a priority on the public agenda. The death of Hollywood actor Rock Hudson, in 1985, was one reason for public recognition of AIDS in the United States. Hudson's popularity as an actor, and the fact that he did not fit the gay male stereotype helped to bring both homosexuality and AIDS out of the closet.

Others began to come forward as well. A woman named Elizabeth Glaser, who had already lost two children to AIDS spoke before a congressional committee while she herself was dying. Ryan White, a teenager, attracted national attention when expelled from his school because it was discovered he had AIDS. And tennis great Arthur Ashe's death from AIDS-related complications (linked with blood he received during a by-pass operation) touched the hearts of many. Likewise, during this time there were many men who, like Danny, had broken the silence surrounding AIDS, and homosexuality, speaking publicly about their illnesses in order to increase awareness and stop the spread of HIV.

Phase Three was marked by the advent of new "miracle" drugs such as Azidothymidine (AZT) and increased funding for AIDS research. AIDS Service Organization (ASOs) had become beehives of activities, and could be found in most cities across the United States. People with HIV turned to ASOs for direct services, support and advice while community groups, schools, clubs (and even medical professionals) made use of ASO's resources, expertise and up-to-date information about HIV/AIDS.

Slowly, funding and AIDS awareness increased. Changes began to be evident. Most notably, the U.S. Food and Drug Administration (FDA) shortened the drug approval process and the drug company Burroughs Wellcome lowered the price of AZT (the only drug then available to

combat HIV) by 20 percent as a result of intense lobbying by ACT UP and AIDS activists (Rushing, 1995; Shilts, 1988). Even though there was still no cure for AIDS anywhere in sight, AIDS activists and caregivers had made a difference in the fight for survival and recognition.

Much had been learned and people were living with HIV and AIDS longer than ever before. ASOs and people living with HIV/AIDS became reservoirs of medical and legal information. Self-help books began to appear, as did personal accounts from long term survivors those, like Danny, who lived beyond the median life-expectancy for people with AIDS. AIDS-related plays such as The Normal Heart (1985), Angels in America (1993), and Elegies for Angels, Punks and Raging Queens (1991) helped foster AIDS awareness and compassion. Films such as Longtime Companion (1990) And the Band Played On (1993) and Philadelphia (1993) recorded the history of AIDS in the United States and helped personalize the crisis. As HIV affected more and more people, there was more family involvement and openness in communities which heretofore had been silent or overtly prejudiced against those with AIDS.

Ostracized and condemned by mainstream churches, gay communities began to reclaim ritual and symbolic expressions of grief, care and solidarity while other public displays provided signs of encouragement and compassion. In 1985, December 1st was established as World AIDS Day and proclaimed "a day without art" to emphasize the devastating losses within the arts communities caused by AIDS. The red AIDS ribbon was commonly worn as a sign of support and commitment to fight against AIDS. The Names Project initiated a widespread community arts project to remember those who had died with AIDS. The name of one who had died was placed on a panel which was decorated in memorial to the person. Individual panels were then stitched together with tens of thousands of other panels, forming an enormous AIDS quilt. The AIDS Memorial Quilt traveled across the nation providing a visual reminder of the numbers of AIDS deaths and the personal losses due to AIDS. I didn't put words to it then, but in retrospect, these

were signs of hope: the affirmation of life, love, community and the strength of the human spirit in the midst of absolute devastation and loss.

By the end of Phase Three, it appeared AIDS had become part of the mainstream of society. This was due, in part, to the sheer numbers of those infected with HIV. In 1993, the United States Centers for Disease Control and Prevention (CDC) reported a sobering statistical picture of the epidemic: of the first 300,000 reported cases of AIDS in the US, the first 100,000 cases occurred over an eight-year period; the second 100,000 cases were reported in just two and a quarter years while the third 100,000 cases of AIDS were reported in less than one and a half years (Geballe, Gruendel & Andiman, 1995). By the end of the first decade AIDS statistics were being recorded in every state in the country; and by 1996, it was estimated that 1 in every 300 Americans was HIV infected (Lather & Smithies, 1997). Interestingly, although rates of infection of HIV were increasing across the nation, Phase Three showed a marked *decrease* in new cases of HIV infection among 'men who have sex with men'. This was attributed to the massive prevention and safe-sex educational efforts within gay communities (Geballe, Gruendel & Andiman, 1995).

When I look back on these years the word "love" comes to mind. The anger and uncertainty of Phases One and Two were still present, but love characterized the years I have named as Phase Three. It was love that channeled the righteous anger of gay communities. As awareness of HIV grew, people began to *see* the faces of AIDS and to feel compassion, a dimension of love. Gay men began to claim a love of self and the gay community like never before. Truly it was love that "came out of the closet" during Phase Three of HIV/AIDS. At the same time, hope was more evident in Phase Three than in either of the previous phases. With experience came knowledge and as that knowledge was shared it offered strength and hope to others. This was a movement built on relationships; hope and love were intertwined.

Phase Four: Children and Women

"Angela"

I first met Angela in 1995 while working at the AIDS Service Center in Bethlehem, PA. She bounced into my office one day, plunked her tiny body into the chair next to my desk and announced her presence: "Hi. I'm Angela." I was immediately taken with this bright, precocious child with her golden brown skin, lively brown eyes and full-faced grin. Assuming her to be the young child of a new client, I offered Angela some crayons and paper, which she readily took. A few minutes later, Angela presented me with two pictures: two hearts, one "happy", the other "sad". She told me that the "happy heart" (the one surrounded by colorful, squiggly lines, stars, balloons and boasting a huge toothy smile) was "the heart that isn't sick anymore". The heart with the frown, the "sad, sick heart" contrasted sharply with the other by Angela's use of browns and foreboding gray clouds surrounding the heart. That was "the heart that's sick, like me" said Angela. *My* heart sank as I realized that Angela was in the office that day to become one of my clients. Angela had AIDS.

Angela's drawings came unprompted and were presented to me with the characteristic 'there, that's it' attitude I would come to know all too well over the next seven months. I would also come to know well the ensuing spasms, raspy coughing and gasping for air that suddenly overtook her just minutes after Angela completed those pictures.

Angela had been born HIV infected, her mother having died from AIDS soon after Angela was born. Angela was born in Puerto Rico and had been adopted as an infant by a Latino family she always believed to be her own. She loved her Mammy and Pappy and the seemingly endless number of cousins, aunts and uncles that frequented her home. When I first met Angela she was approaching her tenth birthday. Like Danny, Angela too was considered a long term survivor, as the median survival age among perinatally acquired HIV/AIDS at that time was 7-9 years (Forsyth, 1995; Kline, 1995).

Angela once said to me, "I always dreamed of having a huge birthday party, with all of my friends and cousins". That was all I needed to hear! With the agency's help, Angela's home care nurse and I organized the party of her dreams, including music, balloons, food, a magician and lots of gifts. Angela later told me that the day of her party had been the happiest day of her life.

For me that September day was bittersweet. On the one hand, it was a delight to see Angela so excited about the party, squeaky-clean and dressed in her Sunday best. On the other hand, she was particularly ill that day. Two major spells of coughing and gasping for breath nearly brought the party to an end. We were celebrating Angela's tenth birthday—just one milestone among many for most children, but a miracle for Angela. I had realized that Angela would never see her next birthday. But as I watched and cared for her that day, I hoped she might live to celebrate Christmas. As it turned out, Angela died just few weeks after her tenth birthday, in the fall of 1995.

Sorrow

Angela was a part of the years I have delineated as Phase Four of the AIDS epidemic in the U.S.: the time when a child's face became the latest depiction of AIDS in the U.S. Children had been a part of the epidemic for many years. At the start of the epidemic, most children had been infected through transfusions of contaminated blood or blood products (Campbell, 1999; Macklin, 1988; Sherr, Elford, Bor, & Hart, 1994). By 1993, however, 93 percent of cases among children were due to vertical, or mother-to-child transmission. By 1990, AIDS had become a leading cause of death for children between the ages of one and four. Among Hispanic children in this same age group, AIDS was the leading cause of death (Geballe, Gruendel & Andiman, 1995). In 1995, the year of Angela's death, the number of reported AIDS cases among children in the U.S. was 6,611 (CDC, 1995), and through 1996, cumulative HIV/AIDS associated deaths among children worldwide numbered approximately 1.4 million (Lather & Smithies, 1997).

The astonishing statistics surrounding pediatrics HIV/AIDS stems from the reality of HIV among women. HIV can be transmitted from mother to child during pregnancy, during labor or delivery, or postnatally through breastfeeding (less likely, but possible). Because they share the mother's antibodies, all infants born to HIV infected mothers carry the HIV virus until developing their own immune system, usually by eighteen months. Approximately one quarter of children born HIV positive will remain infected with HIV after this time. Some children with HIV infection will develop serious signs and symptoms within the first year or two of life. A larger group of children will tend to develop evidence of immunosuppression by the time they are seven to eight years old while a small group remain healthy with minimal symptoms of HIV disease through nine years of age (Pediatric AIDS, 1999).

As stated earlier, the early profile of children and HIV/AIDS included those children who had received contaminated blood or blood products. The reality of perinatal transmission however is that the mother of the infant is herself infected. Thus, the consequences for children infected perinatally are different: there is a high likelihood of parental death.

Another side of the profile of the face of children in the AIDS epidemic is the numbers of AIDS orphans. Even the most conservative projections are astonishing. Over the course of one decade (1990-2000), it is estimated that more than 125,000-150,000 children worldwide will have lost their mothers to AIDS (Geballe, Gruendel & Andiman, 1995). Angela herself was among these numbers as her birth mother died from AIDS. Approximately three-quarters of AIDS orphans will remain uninfected with HIV and motherless. Those remaining orphans will themselves live with HIV infection. The fact that more children in the United States will lose parents to AIDS than to any other cause of death, is already a sobering statistic. Additionally, grief will characterize their early childhood and be a developmental hurdle for many of America's young. One must also consider the impact of other AIDS-related losses that American children

are experiencing in increasing numbers: the loss of brothers; uncles, aunts; neighborhood friends and classmates to AIDS (Geballe, Gruendel & Andiman, 1995).

Angela's infection with HIV from birth, the fact that her birth mother had died from AIDS and Angela's Hispanic racial designation were all reflections of the epidemiological trends of the disease in the early to mid-1990s. According to statistical reports an increasingly disproportionate percentage of African-American and Hispanic women were among those reported as having AIDS. For example, the figures from 1994 show 52 percent of the women with AIDS were African American and 19 percent were Hispanic even though these two groups *together* represented only 21 percent of all women in the US (Lather & Smithies, 1997).

The death of a child is particularly devastating to caregivers, family and friends. Angela's death was a difficult one for any who knew her. The halls of the new pediatric wing dedicated at the local hospital were filled with pictures Angela has colored and given to the staff over the years. There were also framed pictures of Angela herself, both because she was known and loved by all the staff and because she had spent so much of her life there. Her classmates created a panel for the AIDS memorial quilt in Angela's memory: a pink panel decorated with the handprints of each classmate on which were printed messages of love. These tiny handprints surrounded Angela's name and the words "We Miss You". The Catholic Church was filled to capacity for the funeral of that ten-year-old child and the sorrow was palpable. By 1995, the statistics and numbers of those who had already died from AIDS had numbed many AIDS workers. Recognizing the plight of children however, re-opened those old wounds of sorrow, as it was once again evident that AIDS was not going away.

Phase Five: A Time of Hope?!

The previous discussion leads to Phase Five of HIV/AIDS, the phase that gives birth to this project. Phase Five stems from the previous phases and represents the fullness of our

understanding of HIV/AIDS and its widespread impact. Phase Five also brings to the fore the reality of HIV among women.

In 1993 the definition of AIDS was revised to include new opportunistic infections and a lower T-cell count (200 or lower). As in other phases in the history of HIV, this was a marker of changes in the sociopolitical and scientific-medical understandings of HIV. By incorporating gynecological manifestations of AIDS and the lower T-cell count, the revision made it possible for women to be eligible for the now burgeoning AIDS services and treatment (Minkoff, DeHovitz and Duerr, 1995). The change in definition of AIDS brought with it a recognition of the changing demographics of HIV infection and dramatic increases in statistical representation of those infected with HIV and those living with AIDS.

During Phase Five of HIV/AIDS in the United States, heterosexual transmission was becoming the highest risk factor for transmission of HIV, while injection drug use continued to be another leading cause of infection. Women, then, were at risk of acquiring HIV sexually from a partner who injected drugs or who had sex with someone else who may be infected. Women were also at risk from sharing needles themselves.

When I began working at the AIDS Services Center in 1995, the situation of HIV/AIDS among women had become so severe that a new position was created at the agency with the sole mandate of dealing with women and children. At that time, women were the fastest growing segment of the population becoming infected with HIV and the rate of infection was alarming. Between 1986 and 1988 the number of women aged 15 to 44 who died of AIDS rose 75 percent. In 1994 alone there were over 14,000 newly reported cases of AIDS among women in the U.S. In just over a decade, the proportion of all AIDS cases reported among women in the U.S. more than tripled from 6 percent in 1984 to 19 percent in 1995 (Goldstein, 1997; CDC, 1995).

The women comprising my caseload reflected the epidemiological realities of HIV/AIDS in the middle-eastern seaboard of the United States during the mid-1990's. During the year that I

worked in Pennsylvania, the vast majority of new clients at ASC were women. These women predominantly were of childbearing years, poor, Hispanic, newly diagnosed with HIV infection (but not newly infected), horrified and fearful of HIV, and shocked by their diagnosis. By the time I returned to Bethlehem to begin this research, a full range of services had been developed to specifically serve Latinos/as infected with HIV, including two new, separate agencies.

The increasing numbers of women needing to access HIV testing and the services of ASOs during the mid-1990's can be directly attributed to the lack of attention given to women during the early years of HIV/AIDS. Patton (1994, 1990), Singer, MacGrogan, and Butler (1992), Sontag (1988), and others have analyzed the AIDS epidemic as both a viral epidemic and socially constructed metaphor. Each articulates how culturally ingrained stereotypes and myths contributed to the depiction of AIDS (as a gay disease) and to the consequent slow response to the epidemic, particularly in its effects on women. The fact that AIDS had become "an epidemic of signification" (Treichler, 1988a) is one that had far-reaching consequences.

> ...Of course AIDS is a real disease syndrome, damaging and killing real human beings..yet the AIDS epidemic—with its genuine potential for global devastation—is simultaneously an epidemic of a transmissible lethal disease and an epidemic of meanings of signification. Both epidemics are equally crucial for us to understand, for, try as we may to treat AIDS as "an infectious disease" and nothing more, meanings continue to multiply wildly and at an extraordinary rate. (p. 264)

My own experience confirmed this theorizing. Most of the women who attended ASC's women's support group in 1995 had known little about HIV before they became infected, even though by that time HIV/AIDS had been a social reality for nearly fifteen years. Most of these women did not realize that they were at risk when having unprotected sex or sharing needles. Even by the early 1990's, with HIV firmly established as an epidemic in the United States, most women had not heard prevention messages. Neither did they consider themselves to be at risk,

believing HIV to be a "gay disease". Many of the women I worked with in the mid-1990's had questioned their physicians about HIV only to be given responses reflecting the media stereotypes or dismissing their worries. Similarly, many women I counseled had been symptomatic for months before their physicians took notice. In short, only "certain types" of women were believed to be associated with HIV/AIDS.

In conjunction with the uncertainty, anger, love and sorrow characterizing fifteen years of HIV/AIDS in the United States, Phase Five marks the time I began to fully recognize the presence of hope. Soon after I began my work at the AIDS Services Center, I began a women's support group. On any given night, the women gathered would talk about their emotional and physical health. Discussions revolved around children and partners, work and money, friends who were sick and others who were beating the odds. T-cell counts were regular topics of discussion. Likewise, the women also shared tips with one another such as how to deal with the relentless diarrhea associated with HIV infection, the side-effects of their medications, or how to combat weight loss. The word 'hope' was used often, and in different ways: in relation to a child; the next blood test; God; a promising drug trial or a cure for HIV/AIDS. Often the women talked frankly about feeling hope*less* in their struggle with AIDS.

Regardless of the level of intensity or subject matter addressed, or whether the word hope was specifically used, invariably there was a *sense* of hope, experienced in the context of that women's support group. Sometimes hope was clearly articulated: *"I hope I live to see my child graduate"* or, *"I hope my T-cell count goes up"*. Sometimes hope was less obvious. Hope was however, a common theme, whether overtly mentioned or not. Some nights I would come to the support group feeling totally hopeless myself, carrying a full caseload and much heartache over the magnitude of the issues affecting our clients. Repeatedly, I found myself leaving the support group feeling revived, with my own spirits lifted, feeling hope.

During support group meetings there was laughter and the sharing of tears. There were stories of pain and triumph as the women shared their daily struggles. Did hope come through this process of sharing…through the caring and support reciprocated among the participants? Was hope something to be addressed directly? I found myself becoming not only increasingly aware of the presence of hope, but also increasingly interested in hope—the women's and my own. While it appeared that each woman spoke about hope differently, I also noticed commonalties among our descriptions and experiences. I began to wonder about the experience of hope and its power and presence in the lives of women living with HIV/AIDS. How do these women each describe and experience hope? Does hope make a difference in women's lives? How could hope be nurtured among women, particularly when hope appeared absent?

After enrolling in the University of Alberta's Department of Human Ecology intending to study hope, I realized just how much research had already been done with regards to hope and its benefits. Some research had confirmed my own experiences with hope: hope is a "complex intangible" (Jevne, 1993); it is holistic (Farran, Herth & Popovich, 1995); and vital to human well being and life (Frankl, 1959). What had been a spark of interest in hope was fanned into full flame however, as I realized that there was still much to be learned about the personal *experiences* of hope (particularly among women): what is hope like? How is hope differently experienced? What meanings do individuals ascribe to hope? How do people *live* hope? My familiarity with HIV/AIDS and my commitment to exploring hope on a personal level led to the question guiding this study: *What is the experience of hope among women living with HIV/AIDS?*

In spite of the devastating realities of AIDS, the word associated with Phase Five is hope. Indeed there are specific signs of hope in current statistics showing that AIDS deaths have declined among some populations and appear to be leveling among others. Further, the range of treatments now available for people living with HIV/AIDS and the effectiveness of those treatments for many is cause for hope. This is the general context of hope. Couched within the

general context however, are the particular *lived experiences of hope* in the lives of individuals who, like the participants in this study, live with HIV/AIDS on a daily basis.

CHAPTER TWO

HOPE STUDIED: A REVIEW OF THE LITERATURE

The first thing one notices about a diamond is its beauty. Upon closer examination however, one realizes that it is the composite of many angles, which contributes to the overall beauty of the crystal. Focusing solely on one or another of its facets does not take away from the essential character of the diamond; nevertheless, the beauty of the diamond is accentuated by its intricate complexity.

The same is true for the concept of hope. It appears as an uncomplicated word, a complete entity, used often—even haphazardly—in day-to-day parlance. Upon closer examination however, the assumed simplicity gives way to a more profound complexity. For within our culture 'hope' holds both denotative and connotative meaning; it is general and ambiguous while at the same time hope is remarkably personal and specific.

Hope is not a new concept. Literary, philosophical and theological allusions to hope can be found dating back centuries. For example, the contemporary phrase 'opening a Pandora's box' refers to the ancient Greek myth related to hope. Poets have concurrently cursed and sung the praises of hope while philosophers have considered hope as a human virtue, an emotion, and a passion. Moreover, few would dispute the relevance or centrality of hope to Judeo-Christian heritage. In the past three decades however, there has been a resurgence of interest in the study of hope, in particular among health care professionals who have witnessed its significance for health and quality of life. Indeed, the field of hope exploration is vast, including multiple methodologies and varied research perspectives.

This literature review is not intended to provide the reader with a comprehensive overview of the numerous ways in which hope has been explored over the ages. It is important however, to provide the reader with a sense of the content and direction of hope inquiry relevant

to this interpretive inquiry. Because of its discursive, interpretive emphasis, the concern here centres upon how others have defined and conceptualized hope. In particular, my interest is in examining what dimensions of hope have been explored, how the experience of hope has been explained, and how other researchers have described the concept. Because of the contemporary context of this study (namely HIV/AIDS), I have narrowed the focus of this review to include explorations conducted from among a variety of disciplines, but principally those of the later half of this (past) century.

The primary intention of this literature review is to situate this study within the field of existing hope research in defence of the research question *What is the experience of hope for women with HIV/AIDS?* Secondarily, the literature review provides a basis from which to relate the outcomes of this project. The literature is examined in two major sections: *Hope Described and Conceptualized* and, *Hope, Women and HIV/AIDS.*

The first section examines the 'what', 'when', and 'how' of hope under the following sub-headings: *What is Hope? When does Hope Occur?* And, *How Does Hope Happen?* The second section of the literature review addresses the deeper issue of why this particular study of hope is warranted. The second section of the review gives credence to the current exploration by focusing on the literature specifically related to women, hope, and HIV/AIDS. The general heading *Hope, Women, and HIV/AIDS* is divided into the following sub-headings: *Why Study Hope Among People with HIV/AIDS?, Women and HIV/AIDS,* and *Hope and HIV/AIDS.*

Hope Described and Conceptualized

> *"...Here, Carol, let me go first, I want to tell you about hope! 'Cause I really know what hope is!... [pause]... well... [pause] I guess... um... [giggles]... damn Carol, no wonder you're studying this! That's a hard one!"*

One women living with HIV, whom I knew while working as a case manager at the AIDS Services Center, made the previous comment to me upon hearing the title of my research. The

woman's enthusiasm toward the topic of hope was evident, as was her difficulty describing the experience! I have remembered her reaction as I have learned how others have talked about hope and as I myself have tried to put words to the decidedly personal experience of hope.

As evidenced by the HIV positive woman's quote, people often 'know' what hope is but nevertheless find difficulty putting words to the concept. How one defines hope undoubtedly has a bearing on the significance one ascribes to hope and the experience of hope. Is hope a way of thinking (Bettleheim, 1960; Bloch, 1986; Korner, 1970; Stotland, 1969), a way of feeling (Lynch, 1965; Van Kaam, 1976), a way of behaving (Averill, Catlin and Chon, 1990, Lange, 1978) a mode of being (Benzein, 1999; Herth, 1990; Miller, 1991), or some combination of emotions and behaviour? These categorizations become important facets in the overall understanding of the concept of hope and the experience of hope.

What is Hope?

The question, 'what is hope?' has been explored across a wide range of disciplines. The predominance of recent hope-focused research, however, has emerged from the fields of psychology and the biological sciences, in particular nursing. A considerable amount of the research focuses upon the characteristics and structure of the concept, typically among individuals in the context of illness.

A few definitions gleaned from the research represent the variety of ways in which researchers have conceptualized hope. Hope has been described as a 'complex intangible' (Jevne, 1993); 'an elusive concept' (Farran, Herth & Popovich, 1995); and as that which is 'dynamic in nature, continually unfolding and changing in response to life situations' (Herth, 1993). In addition, hope has been described as 'a stimulus for action' (McGee, 1984) and an 'inner readiness' (Rustøen, 1995). These somewhat open-ended statements found in the literature run parallel to other more definitive assertions about hope. Stotland (1969), for example, proclaimed that "[hope is] an expectation greater than zero of achieving a goal." Later, building upon

Stotland's framework, Snyder (1994) presented hope as a thought process 'a cognitive set' linked with the expectation and achievement of goals.

Fluid and elaborate definitions of hope attempting specificity can also be found in the literature. For example, in their work with adolescent oncology patients, Hinds and Martin (1988) concluded the following: "Hopefulness is the degree to which [individuals] possess a comforting or life-sustaining, reality-based belief that a positive future exists for themselves or others" (p. 339). Based on their work with elderly cancer patients Dufault and Martocchio (1985) defined hope as "...[a] dynamic life force characterized by a confident yet uncertain anticipation of achieving a future good which, to the hoping person, is realistically possible and personally significant" (p. 380). Parse's (1999) attempt to describe the structure of the lived experience of hope was even more complex: "[Hope] is anticipating possibilities through envisioning the not-yet in harmoniously living the comfort-discomfort of everydayness while unfolding a different perspective of an expanding view" (p. 15).

Instead of attempting specificity, some definitions have embraced hope's indefinable qualities, utilizing phrases such as the following: [Hope is] 'a sense of the possible' (Lynch, 1965); 'the voice that yearns to say yes to life' (Jevne, 1994); '[that which] springs from the depths of one's being' (Vaillot, 1970). Jevne (1994) addresses four other important yet ambiguous qualities of hope: the symbolic nature of hope; the uniqueness of hope to the individual; the experiential nature of hope and hope's rootedness in personal history (Jevne, 1994, 1991).

Some researchers have emphasized that hope has a dynamic quality. For example, after a study involving adults undergoing bone marrow transplants for leukaemia, one researcher described hope as a process of sustaining an ongoing tension between "dealing with it" and "keeping it in its place" (Ersek, 1992). Ersek named the tension between the two the "dialectic of maintaining hope". The dialectic was an *ongoing strategy* participants used to maintain hope

while undergoing treatments (Ersek, 1992). Earlier, a psychiatrist named Frank Buckly, related that hope was a process involving the acceptance of the paradoxes of life (Buckly, 1977). Similarly, Nekolaichuk (1990) maintained that an individual's 'hoping self' was held in creative tension with the realities of 'learning to live with uncertainty'. Consequently Nekolaichuk described hope as a dynamic, interactive *process* reflected over time by changes in the 'self' and in the constellation of other factors referred to as the individual's 'hoping network'. Thus, the process of hope was described as "the process of maintaining the hoping self" (Nekolaichuk, 1990).

The question *what is hope* is further addressed in the literature by comparing its state and trait characteristics, through an assortment of models of hope, and by comparing hope with other concepts.

Is Hope a State or a Trait?

Described in The Concise Oxford Dictionary (Thompson, 1995) as "the existing condition or position of a person or thing", a 'state' is considered to be transitory or temporary (p. 1360). This differs from a 'trait' which, when associated with persons describes "a distinguishing feature or characteristic" (p. 1479).

The state-trait differentiation of hope emerges in the literature in a variety of ways. While some researchers have claimed that hope can function as both a state and a trait (Averill, Catlin & Chon, 1990; Farran, Herth & Popovich, 1995; McGee, 1984), others have differentiated between the two. Nowatny (1989) referred to hope as an attribute (trait) of an individual having these six dimensions: confidence in outcome; relates to others; future is possible; spiritual beliefs; active involvement; and inner readiness. Miller defined hope as "... a state characterized by an anticipation for a continued good state, an improved state, or a release from a perceived entrapment..." (Miller & Powers, 1988, p.6). Nurse researcher Grimm (1984) conceptualized hope as a 'psychological characteristic' of an individual. Grimm's work included the

development of an instrument to measure both the state and trait dimensions of hope. In the literature, words suggesting the state dimension of hope include those that are situational such as 'anticipation', 'expectation', and 'wishing' (McGee, 1984; Stotland, 1969). Other researchers describe hope as a personal quality using terms such as 'attribute' or 'personality characteristic' (Grimm, 1984; Farran, Herth & Popovitch, 1995).

Suggesting that hope is a trait, a number of inquiries explore the developmental aspects of hope. Erikson (1950; 1964) for example, claims that hope is a 'virtue' and traced its development from infancy through maturation. In fact, "Hope is both the earliest and the most indispensable virtue inherent in the stage of being alive" (Erikson, 1964, p. 115). As a virtue, hope is essential for progressing through other developmental tasks including the ability to overcome disappointments, to consider better prospects, to imagine, and to develop reasonable expectations (Roset, 1999). Hope has its roots in a trusting relationship between infant and mother. According to Erikson (1964), this trusting relationship is foundational for both socialisation and the development of personal hope: "[the relationship with maternal persons] leads to a certain ratio of basic trust and basic mistrust—a ratio which, if favourable, establishes the fundamental human strength: hope" (p. 231).

Along with Erikson, other researchers have recognized developmental factors that influence hope (Lynch, 1965). As children develop, patterns are learned as they handle obstacles toward goal attainment. The cumulative effect of these patterns will influence the development (or stunting) of hope (Snyder, Hoza, Pelham, Rapoff, Ware, Danovsky, Highberger, Rubinstein & Stahl, 1997). Moreover, an individual's ability to hope is influenced by their trust, determination, and memories of past fulfilled hopes (Urquhart-Schlump, 1990).

Along with developmental factors, the *quality* of human interaction throughout childhood has also been shown to have some bearing on hope. Such things as neglect, abuse, and inconsistent parenting can prevent a child from being able to envision goals, set goals, and attain

goals (Snyder, 1994). In contrast, relationships of trust and mutuality contribute to a positive future orientation (Erikson, 1964; Farran, Herth & Popovitch, 1995; Popovitch, 1991; Pruyser, 1986). One study found a correlation between the presence of role models such as teachers, caretakers, parents and friends and the development of hopeful thinking (Snyder, Hoza, et al. 1997).

Whether referred to as a multidimensional dynamic attribute of an individual (Nowatny, 1989) or a cluster of attributes (Farran, Herth & Popovitch,1995), most researchers acknowledge that while hope is indeed situational (a state), hope is also present as an inherent quality, or trait of an individual (Averill, Catlin & Chon, 1990; Herth, 1996). This 'both-and' feature of the state-trait characteristics of hope presents an interesting challenge for researchers, including an attentiveness to the nuances of language and connotative meanings as participants respond to questions regarding hope.

Models of Hope

Given the multiple definitions of hope, and the difficulties in describing hope, it is not surprising that models of hope have also been developed attempting to provide a depiction of the construct. The models are diverse and represent various theoretical perspectives. Moreover, the models range from the simplistic (portraying hope as a unidimensional construct) to the complex (portraying hope as multilayered and dynamic).

Two examples are representative of unidimensional understandings of hope. First is the example rooted in the following assertion: "...hope is an expectation greater than zero of achieving a goal. The degree of hopefulness is the level of expectation or the person's perceived probability of achieving a goal" (Stotland, 1969, p. 2). Stotland's definition provided a conceptual framework emphasizing the cognitive-behavioural dimensions of hope. Consequently numerous studies and measurements of hope were developed based on this model (Erickson, Post & Paige, 1975; Stoner Hope Scale (SHS), 1988; Staats Hope Index [HI], 1989). Stotland's (1969) theory of

hope holds a "place of privilege" in hope research because so many studies use this theory as a starting point (Keen, 2000). Nevertheless, with its heavily weighted emphasis on 'expectation' the model highlights only one dimension of the experience of hope.

Building on Stotland's framework, Snyder (1994) proposed a cognitive model of hope emphasizing individual mental capacity as both the driving force behind hopeful thinking and that which is necessary to achieve goals. In Snyder's model, hope is conceptualized as the sum of two dynamics: the mental willpower (driving force) and waypower (garnering of resources) toward achieving goals. In an earlier context, Snyder, Irving and Anderson (1991) asserted, "Most writers...who have speculated about the composition of the hope process have postulated that it is a unidimensional construct involving an overall perception that goals can be met" (p. 286). Citing twelve publications as examples, Snyder, Irving and Anderson (1991) claimed that what differentiated this schema from previous speculations was the fact that "others did not attempt to explain the means by which goals are attained" (p. 287).

McGee's (1984) model portrays a continuum with hope and hopelessness situated at opposite ends of the spectrum while despair is placed midway along the continuum. This model suggests a close relationship between hope and despair (indeed with some overlapping characteristics) while at the opposite end of the continuum is hopelessness, which "represents the extreme state of despair in which all hope is lost" (p. 40). In this model hope is conceptualized as having both state and trait components, which are prompted in response to a problem, a goal, or an unmet need. Thus, hope is a subjective response to a presenting problem or, in other words, a "stimulus for action" (McGee, 1984).

Rejecting simplistic assertions about hope, a number of researchers have attempted to portray hope as a multidimensional construct. Dufault and Martocchio (1985) described hope as "a multidimensional, dynamic life force characterized by a confident yet uncertain expectation of achieving a future good which, to the hoping person, is realistically possible and personally

significant" (p. 380). These researchers offered a model representing the complexity of hope based on data collected among elderly cancer patients over a two-year time span. The model portrays hope as inhabiting two spheres, (particular and general) and comprising six dimensions (affective, cognitive, affiliative, behavioural, temporal and contextual). The particular and general spheres of hope are represented as two concentric spheres, each divided into six segments. The inner sphere represents particularized hope (hope associated with specific goals or objects) while the outer sphere represents generalized hope (an intangible, inner experience not connected to a specific goal or object). The six dimensions of hope cut across both spheres. In this model, hope is ever present, because the hoping process employs these many dimensions simultaneously.

Offering another way to conceptualize hope, Miller and Powers (1988), posit that hope is "characterized by an anticipation for a continued good state, an improved state, or a release from perceived entrapment" (Miller & Powers, 1988, p. 6). The framework is comprised of ten dimensions of hope: mutuality/affiliation; sense of the possible; avoidance of absolutizing; anticipation; achieving goals; psychological well-being and coping; purpose and meaning in life; freedom; reality-surveillance optimism; mental and physical activation. This model incorporates both state and trait dimensions of the hoping process and was conceived after an extensive review of the literature related to hopefulness. This framework is referenced frequently in the literature because it is the basis for the Miller Hope Scale, a widely used instrument measuring the multidimensionality of hope (Farran, Herth & Popovitch, 1995).

Additional representations of hope have offered alternative ways to describe the construct. Based upon the authors' assimilation of the literature and their own clinical experiences, Farran, Herth and Popovitch, (1995) defined hope in the following way:

> ...Hope constitutes an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way [of] relating to oneself and one's world. Hope has the ability to be fluid in its

expectations, and in the event that the desired object or outcome does not occur, hope can still be present. (p. 6)

This definition forms the basis of an integrative way of conceptualizing hope. In this schema, hope is described as having four central attributes or *processes*: an experiential process (also called the *pain* of hope); a transcendent or spiritual process (the *soul* of hope); a rational process (the *mind* of hope) and a relational process (the *heart* of hope). These categories provide an open-ended and dynamic way to comprehend and describe hope. As well they provide a framework within which to categorize the wide range of hope research.

One unpublished doctoral dissertation offers potential for portraying individual variation of the hoping process within a common framework. Utilizing Osgood, Suci, and Tannenbaum's semantic differential technique (1957), Nekolaichuk (1995) identified a structure based on personal and connotative meanings of hope. Responses were solicited from three groups including healthy adults, adults with chronic and life-threatening illness, and adult caregivers. A structure for the meaning of hope was depicted and was comprised of three inter-related factors: (1) personal spirit (2) risk (3) authentic caring. These three factors emphasized three dimensions of hope: the personal, situational, and interpersonal. This model offered promise for a more fluid way of conceptualizing the individual hoping process.

An additional attempt to portray hope took place in a study among four groups (patients undergoing heart transplant, spinal cord injured patients, breast cancer survivors, and breastfeeding mothers (Morse & Doberneck, 1995). The study utilized concept analysis to identify patterns or typologies from participant responses. Seven abstract and universal components of hope were uncovered. These included:

1. A realistic initial assessment of the predicament or threat
2. The envisioning of alternatives and the setting of goals
3. A bracing for negative outcomes
4. A realistic assessment of personal resources and of external conditions and resources
5. The solicitation of mutually supportive relationships
6. The continuous evaluation for signs that reinforce the selected goals

7. A determination to endure

(Morse & Doberneck, 1995, p. 277).

These seven components were compared across the four participant groups in order to reveal emergent patterns of hope. Four patterns were found: hoping for a chance; incremental hope; hoping against hope; and provisional hope. By their own admission, the authors of the study claim the typologies to be neither comprehensive nor complete. Nevertheless, the seven components are presented as 'filling gaps' in previous models by "delineating certain intrapersonal aspects of hope such as assessment, envisioning, and bracing for negative outcomes" (Morse & Doberneck, 1995, p. 284).

Hope, Wishing, and Optimism

One of the difficulties incorporated into the study of hope is the association of hope with other concepts such as wishing, optimism, desire, faith, love, as well as a variety of other concepts. An examination of salient examples from the literature regarding hope, wishing and optimism will demonstrate the varied attempts to distinguish the concepts.

Pruyser's (1986) assertion accentuates the difference between hope and wishing. The former entails depth of understanding and a relational component while the latter is impulsive and unrealistic.

> To hope, then, one must have a tragic sense of life, an undistorted view of reality, a degree of modesty vis-à-vis the power and working of nature or the cosmos, some feeling of commonality, if not communion, with other people, and some capacity to abstain from impulsive, unrealistic wishing. (Pruyser,1986, p. 122)

Lange (1978) states that wishing and desire are similar as they both "…[crave] a possession which is attractive but not essential" (p. 173). Wishing (and desire) are more superficial than hope which "is more central to important needs and reflects wishes that might come true" (p. 173). Similarly, Dufault and Martocchio (1985) contrast wishing and hoping by

stating the following: "A wish differs from a hope in that it is not perceived as within the realm of possibility in the present or future" (p. 385).

Korner (1970) stresses that the difference between wishing and hoping is commitment and need:"[individuals] are tied to their hopes; they need them, they resist losing them; they fight to maintain them" (p. 136). Marcel (1978) also believes that wishing entails specific objects of desire whereas hope is characterized as a general existential condition. Marcel distinguishes between "real" hope and a "mere platonic wish" (p. 35) by contrasting the phrases "I hope . . ." and "I hope that . . ." Hope "tends inevitably to transcend the particular objects to which it at first seems to be attached" (Marcel, 1978, p. 2). For Marcel the distinction is essential. The phrase "I hope" reflects the deeper realities of the hoping process, whereas "I hope that . . ." moves hope from a state of *being* to a state of *desiring*.

Marcel also distinguishes between optimism and hope: optimism is egocentric but hope is not. The optimist, according to Marcel is a "maker of speeches", considering the situation "from a significant distance" rather from "the most intimate and living part of [oneself]" (1978, p. 34). Referencing Marcel, Pruyser (1963) states, "optimism refers to externals, outside the intimacy of the self . . .and is only possible when a person takes a position some distance from reality" (p. 89). Likewise Aikman, (1995) asserts: "Hope is definitely not the same thing as optimism. It is not the conviction that something will turn out well, but the certainty that something makes sense, regardless of how it turns out" (p. 11).

In Hope and Hopelessness: Critical Clinical Constructs (1995), Farran, Herth and Popovich spend a considerable amount of time differentiating between wishing, hope and optimism. The authors systematically compare and contrast the three concepts by applying the four attributes of their model of hope: the spiritual, relational, rational and experiential. Contrasting the components of wishing, optimism and hope in relation to the four attributes help distinguish between the three concepts, which the authors see as being qualitatively different.

When does Hope Occur?

Morse and Doberneck declared, "...Unless there is a threat that is acknowledged and assessed, hope does not exist" (1985, p. 281). However strongly worded, this was not a new insight. In 1970, Vaillot posited that hope begins when personal resources are exhausted. Echoes of these sentiments can be heard throughout the hope literature, the vast majority of which assumes the following: "...hoping presupposes a tragic situation; it is a response to felt tragedy, and is the positive outgrowth of a tragic sense of life" (Pruyser, 1986 p. 122).

Some of the most profound essays and explorations of hope were formulated as reflections upon horrific or stressful circumstances. Victor Frankl (1959) wrote about hope as it arose from within his experience of a Nazi concentration camp. Moltmann (1975), Fromm (1968) and Marcel (1978) also explored hope from situations of turmoil including prisoner of war camps, and the aftermath of WWII. Their personal experiences as well as their common assertion that hope is rooted in some form of 'trial' or 'suffering' informs and permeates their work.

A diagnosis of a chronic or terminal illness is often experienced as a tragic situation. Likewise, persons experiencing chronic or terminal illness are challenged to maintain hope in the midst of uncertainty while living with debilitating and oftentimes painful diseases. Consequently, the vast majority of research exploring the phenomenon of hope has taken place among those who are ill.

Because of its association with times of crisis, hope has been vigorously studied in health care settings, and among health care professionals and psychologists who work with ill populations. Hope research among the seriously and chronically ill include studies conducted with stroke patients (Popovich, 1991); adolescent and adult oncology patients (Hinds, 1988; Raleigh, 1992; Hinds & Martin, 1988) and bone marrow recipients (Ersek, 1992). Hope research among terminally ill populations include Herth's (1990) study among terminally ill adults (including in the sample men with AIDS), Hall's (1990) study among persons with HIV, and

Perakyla's (1991) study conducted in Finland among patients with leukaemia. Research has also been conducted among families of those who are critically ill (Herth, 1993; Miller, 1991), caregivers (Herth, 1993),and among the homeless (Herth, 1996).

Hope and Hopelessness

The importance of hope to health and well being is an assumption permeating the literature. Conversely, hopelessness has been linked with isolation, grief, loss of control, depression, suicide, and linked to specific situations such as when individual health is challenged (Beck, Weissman, Lester, & Trexler, 1974; Beck, Steer, Kovacs & Garrison, 1985; Farran, Herth & Popovitch, 995; Lynch, 1965; Melges & Bowlby, 1969). The following definition contrasting hopelessness and hope conveys sentiment abounding in the literature: "hopelessness is the state of acute or prolonged desperation which represents the feeling of being beyond hope—irredeemable, irreversible, incurable and incorrigible" (Lange, 1978, p. 173). Lynch (1965) describes three core feelings contributing to sense of hopelessness: the sense of the impossible; the feeling of *too muchness*; and what Lynch calls 'a powerful lack of feeling', the sense of futility. According to Lynch, it is the *combination* of these three factors which produces hopelessness.

Hope and hopelessness, are often discussed in association with one another (Farran, Herth & Popovitch,1995; Fowler, 1995; McGee, 1984; Miller & Powers, 1988; Nowotny, 1989). At the very least, researchers have noted a congruency and relationship between the two. Throughout the literature the tendency has been to view hopelessness as the negative counterpart to the more positive hope. Nurse researcher McGee (1984) states the contrast in this way: "Without hope, the person is dull, listless, moribund, present oriented, and hostile. Hope implies freedom, adaptability, control, and imagination (p. 38).

Though they are often discussed in conjunction with one another, research has not made explicit the relationship between hope and hopelessness. The tendency among researchers is to view hopelessness as either the polar opposite of hope (Stotland, 1969; McGee, 1984) or in

dialectical relationship with hope (Kylmä, & Vehviläinen-Julkunen, 997; Lynch, 1965; Farran, Herth & Popovitch, 1995). Farran, Herth, and Popovitch, (1995) assert that hope and hopelessness are closely related but different experiences. The authors describe hope and hopelessness as sharing the same attributes namely: experiential, relational, spiritual, and rational. Others have shown that developmental factors and situational determinants influence both hope and hopelessness (Erikson, 1982: Lynch, 1965; Fromm, 1968).

The terms hope and hopelessness are frequently compared and contrasted in the literature. Lynch, for example claims that hopelessness is a sense of the impossible, a type of checkmate, as opposed to hope, which is characteristically a sense of the possible (Lynch, 1965). Likewise, Stotland's work (1969) contrasts the action and future orientation of hope with the negative view toward the future in the thought processes of the hopeless. Highlighting the relationship through the title of the book Hope and Hopelessness: Critical Clinical Constructs, Farran, Herth, and Popovitch, (1995) even go so far as to suggest that hopelessness, like hope, is "an essential experience of the human condition" having cognitive, affective and behavioural components (Farran, Herth & Popovitch,1995, p. 24-25). The authors synthesize the literature and delineate the concepts in a way that portrays hope and hopelessness as more alike than different, with the experience of one illuminating the other.

Clinicians and researchers have considered hopelessness to be decidedly more measurable and concrete than the elusive hope. Based on this, and the assumption that hope and hopelessness are related, researchers have used hopelessness to help clarify the concept of hope. The Beck hopelessness scale (Beck, Weissman, Lester & Trexler, 1974), a twenty-item dichotomous questionnaire, is frequently used both to validate hope measures and as an indirect measure of hope (Rabkin, Neugebaur & Remien, 1990; Parse, 1999; Zich & Temoshok, 1987). However, this and other hopelessness scales are based upon a unidimensional understanding of

both hope and hopelessness and do not embrace multifaceted conceptualizations of either construct.

Whether viewed as the opposite of hope or as integral to the experience of hope, significant attention has been given to hopelessness among the research related to hope. Given the terminal potential of AIDS, the stigma associated with HIV/AIDS, the young age at which most are stricken, and the lack of clearly defined treatment options and outcomes, hopelessness becomes an important part of the conversation about hope in the midst of HIV/AIDS.

How Hope Happens

Vaillot's (1970) assertion that hope "springs from the depth of one's being" sparks the question: how does that happen? Marcel's (1978) statement, "One wonders if despair and solitude are not at bottom necessarily identical" (p. 58) and Jevne's (1991), "Hope is given and received through human relationships" (p. 149) represent two sides of the same coin, and a theme commonly found within the hope literature. Whether referred to as the relational dimension, the spiritual dimension or the interpersonal characteristics of hope, the consensus appears to be that hope does not happen in isolation. Hope cannot sustain itself on its own. Hope is dependent upon resources, whether these are spiritual, physical, emotional, and social (Roset, 1999).

Hope and Relationships

The importance of relationships in fostering and nurturing hope has become a strong theme within hope research. Pruyser (1963) claims, "the language of hoping is filled with verbs of relationships and receptivity. A hope is found, it is given, it is received. . .Hoping is basically a shared experience" (p. 95). As has been shown earlier, many studies of hope concentrate on individual personal characteristics which may engender hope, and highlight the situational conditions under which hope occurs. Paralleling these studies are those which explore the *interpersonal* dimensions of hope: the link between individual hope and relationships with others.

Farran, Herth, and Popovitch, (1995) claim that indeed one of the four attributes of hope is its relational dimension. Nowatny (1989) states that "hope relates to or involves other people or a higher being" (p. 58). Miller and Powers (1988) glean from the literature the designation of "mutuality/affiliation" as one of ten essential components of hope. In Dufault and Martocchio's (1985) work among elderly cancer patients all participants name the behaviour of significant others as sources of hope. Jevne (1993) suggests that hope is always experienced in relation to someone or something be it a person, theological belief, or person: "Basically, hope is a shared experience; it is difficult to hope alone" (p. 124).

One Swedish study involved a series of phenomenological studies conducted among healthy religious and non-religious people, oncology nurses working with patients with cancer, and patients with cancer in palliative home care. Regardless of background, all participants linked positive relationships as critical to their lived experiences of hope. Interestingly, these relationships were named as intrapersonal (being in touch with one's own thoughts and feelings, having control and liking oneself as a person), inter-personal (family, friends, pets, and one's surroundings), and transcendent (God, a higher being, or some undefined spirituality) (Benzein, 1999).

In a study conducted among nurses who work with mental illness, Byrne, Woodside et al. (1994) utilized the ten elements constituting hopefulness as defined by Miller and Powers (1988) and surmized three key factors that may foster hope via relationships. First, it was discovered that an individual could be mobilized to maintain hope *through relationships with others* (in this case a nurse). Secondly, *relationships* seem to be "the catalyst that allows hope to develop exponentially". The third key point was that a powerful motivator for change is the belief *(held by another)* in the client's abilities (Byrne, Woodside et al., 1994, p. 34, emphasis mine).

By altering a well-known quote, Miller (1985) emphasizes the nurse's role in inspiring hope by proclaiming, "hope doesn't necessarily spring eternal—sometimes it has to be carefully

mined and channelled" (p. 23). Consequently, Miller (1985) suggests eight hope-inspiring strategies nurses can employ:

1. Emphasizing sustaining relationships
2. Telling the patient that loss of control is temporary
3. Radiating hope
4. Expanding the patient's coping repertoire
5. Teaching reality surveillance
6. Helping the patient devise and revise goals
7. Helping the patient renew his/her spiritual self
8. Guarding against despair

(p. 24)

Stoner (1988) claims the following: "Although hope remains poorly understood, nurses are frequently encouraged to instil, inspire, and maintain hope as a therapeutic intervention with patients" (p. 138). Using grounded theory among terminally ill HIV patients, Cutcliffe (1995) surmises that hope is inspired as the nurse and patient enter into a "partnership, underpinned by the affirmation of the individual's worth" (p. 888). Thus, Cutcliffe (1995) concludes, "The presence of another human being who conveys unconditional acceptance, tolerance and understanding should not be under-estimated in terms of its therapeutic value and foundation for hope inspiration (p. 894).

It is not only nurses who are in a position to foster hope. Other health care professionals, family members and caregivers can make a difference when one's hope is challenged (Herth, 1993; Hinds, 1988; Jevne, 1993; Keen, 1994; Perakyla, 1991;Wong-Wylie & Jevne, 1997). In her study of hope in the family caregivers of terminally ill adults, Herth (1993) reported that the most frequently identified "sources" of hope were: family, friends, health care professionals and God/higher power (p. 342). Moreover, studies suggest that the *quality* of relationships may also have a bearing on the fostering and nurturing of hope, aptly termed a "credibility component" (Nekolaichuk, 1995; Cutcliffe, 1995).

The importance of relationships both to the experience of hope and in fostering hope presents an intriguing dimension of hope and widens the scope of research possibilities. The relational aspects of hope engender questions such as the following: what kinds of relationships are considered hopeful? What are the contexts of interactions fostering hope? What types of interactions are considered hopeful? Furthermore, explorations into the particularities of the relational related to spirituality are warranted. The significance of the relational dimension of hope to the current research is assumed based upon three assumptions: 1) the context of women's lives is often characterized by our relationships with others 2) living with HIV/AIDS necessitates relating with multiple environments and 3) meaning itself is relational, based upon mutual understandings.

The Experience of Hope

Phenomenology is concerned with everyday 'lived' experience. It addresses the question: what is [a phenomenon] like? Though not designated as phenomenological, many explorations of hope have nevertheless attempted to describe the experience. Because hope has most often been linked with the attainment of goals, many describe hope as a course of action or process, oriented to the future. (Farran, Herth & Popovitch, 1995; Herth, 1996; Nekolaichuk, Jevne & Macguire, 1995). In her work among young cancer patients, Pamela Hinds (1988) defines hope as "the degree to which adolescents possess a comforting or life-sustaining, reality-based belief that a positive future exists for themselves or others" (p. 85).

Dufault and Martocchio (1985) include this statement in their definition of hope: "...Hoping is not a single act but a complex of many thoughts, feelings and actions that change with time" (p. 380). Participants in a study of hope among a homeless population "...[described] hope as an ongoing process that arises from within and from outside self" (Herth, 1996, p. 749). Fowler (1995), claims that "hope is a process of growth and adaptation" (p. 302). According to Pruyser (1986), Marcel (1978) believes that hope should be explicated as a *verb (hoping)* rather

than a noun (hope) "in order to accentuate its process character and to make [hope] amenable to introspection" (p. 121).

Some have examined hope as a process made up of two dynamics: an *orientation* that motivates vision and *action* that goes beyond individual needs. Menninger (1959) acknowledged the process orientation of hoping by describing hope as a movement toward the realization of human potential. Other theorists echo these sentiments, emphasizing the potential for hope to mobilize one's resources toward a greater good, toward actualization of a better place for oneself and for the world (Fromm, 1968; Moltmann, 1967; Havel, 1965). Based on his experiences in a Nazi concentration camp, Victor Frankl's (1959) memorable work equates hope with a basic human drive: the search for meaning.

These sentiments attempt to distinguish between hope as a way of *being* and hope as *doing*. *Doing* may be more specific, goal or action oriented, with a focus on the future. Conversely, the *being* constituent of hope may be more internally focused, less specific and more oriented to the present. Surprisingly few studies have brought this distinction to light. Justifying the development of a new instrument to measure hope, Herth (1992) reveals that a number of conceptual issues remain outstanding including, ". . .a more global, non-time-oriented sense of hope. . .[and]hope as a sense of 'being' available ...as opposed to 'doing' for oneself and others. . ." (p. 1252). In an earlier study among terminally ill individuals, Herth (1990) observes a notable absence of the word 'future' in participant's descriptions of hope. In a later study, conducted among homeless people, the following is offered: "Several described focusing less on the future and more on living one day (one hour, one moment!) at a time"; therefore the emphasis is on being rather than doing (Herth, 1996, p. 543).

One recent phenomenological study, undertaken in Sweden, explored the experience of hope among four groups, including religious and non-religious, ill and well individuals. The study related that among the varied and changing dimensions of the lived experience of hope, two

were prominent: *being in hope* and *having hope for something.* Being in hope was an inner process expressed as a sense of belonging and relatedness, both to oneself and to the world. Having hope for something included goal setting (doing something) and a sense of risk-taking. *Being in hope* was described as a precursor to having hope for something. These findings pave the way for other phenomenological explorations, with the researcher concluding that "the phenomenon of hope as a lived experience per se remains a mystery..." (Benzein, 1999, p. 20).

Women, Hope, and HIV/AIDS

In the attempt to define hope and delineate its characteristics, I have provided an overview of the literature related to the 'what', 'when', 'where' and 'how' of hope. Typically, the motivation for much of the research is set forth by making a correlation between hope and health, hope and well-being, and hope and a sense of meaning (Cousins, 1989: Frank, 1968; Frankl, 1959; Hall, 1990; Herth, 1990; Jevne, 1990; Marcel, 1978; Nekolaichuk, 1995; Owen, 1989; Pruyser, 1963).

The situation of HIV/AIDS presents an individual with much more than a prognosis regarding physical health or decline. To be sure health and well-being are in the forefront of concerns for those who are HIV positive. For many individuals and families however, HIV/AIDS presents not only a physical crisis but also a crisis of meaning. Some authors describe the diagnosis of AIDS in a family member as more devastating to families than other illnesses because of the social stigma attached (Brown & Powell-Cope, 1991). Moreover, levels of hope have been found to be lower among those with AIDS than the cohort participants suffering from other illnesses (Herth, 1992, 1993). In spite of its effects on individuals and families across North America, the experience of hope in the context of AIDS has remained understudied among hope researchers.

Women and HIV/AIDS

In his seminal work And the Band Played On (1988), Randy Shilts reported that one of the first reported causalities of what was to become known as AIDS was a Danish physician, who had served in Africa, and was a woman. Dr. Grethe Rask died in 1977. In the United States, there were reports of women dying of AIDS-related complications as early as 1981. The CDC reported women with AIDS-related conditions during the first years of the epidemic. According to Singer (1994), the CDC reports contained "no full-scale analysis of women and HIV/AIDS until a report in 1987 addressed seroprevalence among prostitutes" (p. 11).

Gena Corea's (1992) compellingly titled book, The Invisible Epidemic traces the chronology of HIV/AIDS as it affected women during the first decade of the epidemic in the United States. Although the topic of women and HIV/AIDS can be found in a few (primarily medical) journals in the late 1980's, Corea's book stands among the first books published exclusively on the topic of women and HIV/AIDS.

Until well into the 1990's it was difficult to find medical information specific to women: "...Despite a continuing trickle of reports and case notes in the medical and social work literature, concern about the nature of women's clinical progress did not consolidate into a research enterprise until 1990..." (Singer, 1994, p. 12). From the mid-1980's to the end of the first decade of AIDS in the United States, the literature reflects increasing attention to paediatric AIDS, perinatal transmission, HIV among prostitutes, and HIV infection among African or Haitian women. Few resources addressed the *particular* medical or social needs of women in general (Buzy & Gayle, 1996; Cohen & Durham, 1993; Goldstein & Manlowe, 1997).

In reaction to the dearth of resources available for women ten years into the epidemic, women's groups, women physicians and women activists began to pour out information specific to women and women's concerns. See, for example, Berer and Ray, (1993), Kurth (1993), Miller, Turner and Moses (1990), Rudd and Taylor, (1992), and Squire (1993). Because women's

concerns were finally being addressed, the appearance of these resources marks a turning point in resources focusing on women. Nevertheless, none of these books directly addressed the topic of women, HIV, and hope.

Feminists have long maintained the differences between women's experiences and men's. Some of the research mentioned in this literature review touches on gender differences with regards to hope and the hoping process. Interestingly, the vast majority of researchers exploring hope have been women although few have focused their research among women.

The now burgeoning amount of literature regarding women and HIV/AIDS is a welcome, necessary and important addition to the body of knowledge surrounding HIV/AIDS. That much of the literature has been published more recently also reflects two characteristics of the past two decades: women continue to be affected by HIV/AIDS and women are moving towards the centre as important voices in the epidemic. With its emphasis on experience, its descriptive, storied accounts of the lives of the five participants an by its contextual approach, investigations such as this will round out the current body of literature by continuing to call attention to the particularities of women's lives and women's experiences. This is needed now as much as any time during the epidemic.

Hope and HIV/AIDS

Hope has been a theme of the AIDS epidemic from its earliest appearance in the US. There is however a paucity of research about the experience and meaning of hope as it is lived by people with HIV/AIDS. Given the scope and enormity of the AIDS epidemic in the United States, it is surprising that few studies have investigated hope in the context of HIV/AIDS.

Carson, Soeken, Shanty and Terry, (1990) explored hope in its relationship to spiritual well being among people with AIDS. Their findings emphasized the need to sustain hope in the midst of this chronic, terminal illness. Using both the Beck Hopelessness Scale (Beck, Weissman et al., 1974) and the Spiritual Well-Being Scale (Ellison, 1983), Carson et al. (1990) found their

sample of sixty-five males to be both hopeful and spiritually well. Indicating some caveats to their findings, such as the fact that their convenience sample was comprised of men undergoing treatment at a prestigious research centre, the researchers pose interesting thoughts about the homosexual experience of organized religion and their findings. Particularly, "...[These] gay men do not achieve their hope and spiritual well-being as a result of religious well-being, but primarily through existential well-being" (Carson et al., 1990, p. 33). This study did not investigate further the meaning of "existential well-being".

Utilizing the Beck Hopelessness scale (Beck et al., 1974) among HIV positive men, Rabkin, Neugebaur and Remien (1990) explored hope as a protective factor in the progression of HIV disease. Although a correlation could be made between levels of social support, a sense of control and levels of hopelessness, a correlation could not be made between HIV status, T-cell counts or physical symptoms and hopelessness (Rabkin et.al., 1990). Zich and Temoshok (1987) conducted a study of hope among men living with HIV/AIDS utilizing the Beck Hopelessness Scale (Beck et al., 1974). They found lower levels of hopelessness among those individuals who either had increased perception of available social support or actually made use of social supports available to them.

Hall's (1990) work with eleven seropositive men resulted in definitions of hope and descriptions by the informants of the strategies used to maintain hope. Referencing Mishel (1988), Hall referred to these strategies as affect-control strategies, or attempts to control emotion and manage fears in the midst of uncertainty. The eleven men nearly universally agreed upon the meaning of hope, which involved the following:

- Having a future life in spite of the diagnosis.
- Having a renewed zest for life.
- Finding a reason for living, usually one that was not evident before.
- Finding a treatment in the professional or alternative care system that one believes will contribute to survival.

(Hall, 1990, p. 183)

According to Hall (1990), the participants found difficulty in "establishing an inextricable interconnection between the present and the future, and a strong feeling of optimism often in the face of dire predications" (p. 183). In another study, Hall (1994) used interpretive interactionism to guide her analysis of data collected among ten adults living with AIDS. The following four ways of maintaining hope were identified: miracles, religion, involvement in work or vocations, and the support of family and friends.

In a study of meaning in the lives of people living with HIV, Doris Coward (1994) made the claim that, prior to hers, there had been only one study exploring *women's* experiences of HIV/AIDS. The focus of that earlier study however was on *mothers* whose sons died of AIDS (Coward, 1994). Coward's study unearthed hope as one of a number of themes related to meaning in the lives of both men and women with AIDS. Her study did not however, explore hope in any greater detail. One recent study, conducted among economically advantaged and relatively well-educated women, examined hope as *part of* the coping mechanism of women living with HIV/AIDS. Again, hope was not explored in detail (Nannis, Patterson & Semple, 1997).

Among the limited research exploring hope in the context of HIV/AIDS, emphasis has not always been placed solely on the individual living with HIV/AIDS. For example, one study took place among family caregivers of those with HIV/AIDS (Herth, 1993), one study was specifically directed toward nurses and nursing practice among those with HIV/AIDS (Hall, 1990) and another focused on patient and physician interaction (Wong-Wylie & Jevne, 1997). Another study among terminally ill HIV patients examined how nurses instil and inspire hope in their patients (Cutcliffe, 1995).

Not surprisingly, among the studies involving persons with HIV/AIDS the samples were primarily heterogeneous (male and female participants) or exclusively male. Up until a very recent time, one would be hard pressed to find literature on any topics related to women and HIV/AIDS. The early part of the 1990's shows repeated references to *the lack of* research

focusing on women and HIV/AIDS and demands for change (Amaro, 1993; Cohen & Durham, 1993; Fee & Kreiger, 1993). Today the amount of HIV/AIDS resources in general is astounding; the ever-expanding number of books attending to women and HIV/AIDS indicates both an increased awareness of HIV/AIDS among women and the continued prevalence of the disease.

Conclusion

In 1959, while addressing the American Psychiatric Association, Karl Menninger sounded a rally cry regarding the study of hope:

> Our shelves hold many books now on the place of faith in science and psychiatry, and on the vicissitudes on man's efforts to love and be loved. But when it comes to hope the journals are silent. The Encyclopaedia Britannia devotes many columns to the topic of love, and many more to faith. But hope, poor little hope! She is not even listed. (Menninger, 1959, p. 447-448)

Since Menninger's time there has been a proliferation of research focusing on hope. Definitions, theoretical models, measurements of hope and reflections about hope abound, spanning multiple disciplines. These studies have added to the wealth of knowledge about hope and have contributed a certain degree of understanding about the dynamics of hope and the hoping process. Still, as one wades into the sea of research emerging during the past four decades, one realizes that there is still much to learn about hope.

The multiple ways in which hope has been defined and conceptualized may at first glance appear confusing. It is evident that there is neither consensus regarding hope's characteristics nor consistent language used to describe the topic. The attempts at definition, model development, and description certainly have their benefits. These attempts provide language with which to talk about hope and together the definitions of hope go far in describing the construct of hope.

Moreover, the scope and multiplicity of definitions confirms the variation in experience associated with this phenomenon.

The conceptualizations fall short however, in two important respects. Although engaging, the definitions of hope are nonetheless ambiguous and far-reaching. Even acknowledging the elusive character of hope and the difficulties in describing hope, the definitions highlighted in the literature may be so ambiguous that they can be applicable to "other" concepts such as faith, friendship, or love (Morse & Doberneck, 1995). Moreover, because there is little agreement about definitions, terminology, or the assumptions regarding hope, each conceptualization must be examined separately and makes sense solely by its own terms of reference. For example, the core concept of "personal competence" named by Hinds and Martin (1988) as crucial to the process of achieving hopefulness is not comparable to Nekolaichuk's (1995) similar sounding "personal spirit". While both attempt to provide a framework structuring hope, one presents hope as part of the self-sustaining process (Hinds & Martin, 1988) while the other emphasizes personal meaning (Neholaichuk,1995).

A preponderance of literature related to hope conveys a future orientation and the process-nature of hope. Nevertheless, many questions remain unanswered. Specifically, the relationship between the past, present and future in the experience of hope has not been clarified. Moreover, research has yet to make explicit any correlation between changes in *orientation* to time (such as during the course of illness) and the experience of hope. Many assumptions about time underlie current hope research. Certainly there is room for explorations centring on varied cultural experiences of 'time' in relation to the experience of hope as well as phenomenological explorations into the experience and meaning of hope at varying points in time.

While rich and diverse in the approaches of study, the conceptualizations of hope demonstrate that a universal definition of hope continues to elude researchers. Indeed a universal definition of hope may not be possible. This situation can either present confusion and cause for

concern or it can represent a dynamic field rife with opportunities for further inquiry into the mechanisms and characteristics of hope. The latter position becomes relevant to the current research endeavour. The multiplicity of ways in which hope is defined and conceptualized neither negates the necessity for further explorations nor constrains further inquiry into the experiences of hope among individuals. Rather than creating a problem to be overcome, the fact that there exists no universal definition of hope confirms the need for continued explorations of this highly personalized yet universally experienced phenomenon.

This review of the literature demonstrates the wide variety of research focusing on hope, with most of the literature emerging in recent years. Definitions, theoretical models, measurements of hope, and reflections about hope abound, spanning multiple disciplines. These studies have added to the wealth of knowledge about hope and have contributed a certain degree of understanding about the dynamics of hope and the hoping process. As one wades into the sea of research emerging during the past three decades, however, one realizes that there is still much to learn about hope. There is much to learn because hope is both an oftentimes taken-for-granted reality and that which "comes close to being the very heart and centre of a human being' (Lynch, 1965 p. 31).

The limited attention given to the experience of hope among persons living with AIDS and, in particular, hope among women with HIV/AIDS supports the need for further explorations such as the current undertaking. With its particular focus on women, and its phenomenological orientation, including the interpretive focus, this study provides a unique contribution in and the psycho-social dynamics of living with HIV/AIDS both of these major areas as well as contributing to the existing research and literature on hope.

CHAPTER THREE

A CONFLUENCE OF STREAMS

This chapter presents three paradigms that form the theoretical underpinnings of this project: 1) human ecology 2) feminism and 3) hermeneutic phenomenology. Important assumptions from each of the paradigms are introduced and discussed in relation to the research question: *What is the experience of hope among women with HIV/AIDS?*

Because the three currents of thought merge and intertwine, this chapter is entitled "A Confluence of Streams". The image portrayed in the title of this chapter is appropriate for this discussion. Separately each paradigm forms its own stream—currents of thought which have been carried along from a distant past. The insights and works of its inquirers are the tributaries feeding each stream. The three streams of thought are not static; there has been movement. Each stream has changed direction along the way, having been altered by its interactions and confrontations with people's experiences, variety in cultures, other paradigms and the shifting sands of time. As the streams meet a confluence is created: one spot, one moment in the life of each stream as their waters carry on.

The Stream of Hermeneutic Phenomenology

The merging of the two terms 'Hermeneutics and 'Phenomenology' represents the partnering of two distinct, complex, and rich traditions. The former has its roots in Biblical interpretation, the latter through philosophy. Together they represent one of the 'streams' that provide the theoretical framework of this study. As phenomenology, the study describes the experience of hope, and addresses the question: what is hope like for the five participants? As a hermeneutic, this study is also interpretive, and addresses the question: what is the meaning of the experience of hope? As a hermeneutic-phenomenological study, these two questions (What is hope like? And, What does hope mean?) are not considered separately, but in tandem, each intimately bound with the other.

Phenomenology

The term 'phenomenological' has been applied to a broad range of qualitative research. Not all phenomenological studies, however, reflect the same methodological approaches or epistemological assumptions. Generally phenomenological research is divided between two "camps": those aligning with Husserlian phenomenology (transcendental/positivist) and those aligning with Heideggerian phenomenological traditions (existential/hermeneutical) (Koch, 1996; van Manen, 1994). Recognition of this distinction is critical, making all the difference in the approach to phenomenological research, methodological considerations, and to the outcome of the inquiry.

The work of Edmond Husserl (1859-1938) is often cited as the beginning of phenomenology: the study of the life-world (lebenswelt) or human "lived-experience". More specifically, for Husserl and others, phenomenology is the study of everyday phenomenon in order to uncover their underlying structures or "essences". This simple definition and phenomenology's link with Husserl does not begin to convey the complexity of the variety of phenomenological tradition(s) or the contributions of other philosophers to this mode of inquiry. Husserl's student Martin Heidegger (1889-1976), for example, diverged from his teacher in important ways. In fact, the two philosophers have come to represent divergent perspectives, as Husserlian phenomenology is associated within positivism while Heideggerian phenomenology, on the other hand, is more comfortably situated within constructivism. Together Heidegger, Husserl (and later Hans Georg Gadamer) represent the German school of phenomenology, but strongly influential in the field as well are Maurice Merleau-Ponty (1908-1961), Jean Paul Sartre (1905-1980), Paul Ricoeur (1913-), and Emmanuel Levinas (1906-1995), the French phenomenologists as well as the Dutch phenomenologists F.J. Buytendijk (1887-1974) and Jan Hendrik van den Berg (1914-).

Examining two key concepts can delineate some of the differences between Husserlian and Heideggerian phenomenology: the search for essences and the concept of bracketing.

Essences

Some maintain that phenomenology is the search for 'essences'-common structures of an experience-which can be delineated through a process of sequential steps (Coliazzi, 1978; Giorgi, 1985; Polkinghorne 1989). Typically after the interview process, transcripts are broken down into fragments (meaning units) and assigned themes. The themes are then reassembled resulting in description of the underlying structure or essence of the experience. This type of phenomenological reduction is associated with Husserlian phenomenology: pure description, in search of essences following Husserl's oft-quoted mantra, Zu den Sachen, "to the things themselves" (Husserl, 1911/ p. 116).

In contrast, phenomenological inquiry aligned with Heidegger is interested in understanding, with a movement away from methodological rigidity toward an interpretive approach. Rather than approaching the study from a point of objectivity, the researcher is understood to be firmly in the midst of the research. The process of research is reflexive, acknowledging both the social/dialogical construction of meaning and the interpretive dimension of the research process. These types of explorations do not seek "basic structures" underlying an experience but rather seek to ". . .construct an animating, evocative description (text) of human actions, behaviours, intentions, and experiences as we meet them in the lifeworld" (van Manen, 1994, p. 19).

Bracketing

The second concept commonly associated with phenomenology is that of "bracketing". Typically associated with phenomenological explorations, bracketing involves the placing of one's presuppositions to the side, suspending what one already knows about a subject, allowing for a purity of description of the phenomenon and objectivity. It is commonly assumed that

bracketing is a central tenet of phenomenology (a methodological essential) but the philosophers themselves had conflicting opinions regarding bracketing. Hussserlian phenomenology maintains that a system (and standard) of bracketing one's assumptions and prejudices allows for pure description of the essence of the phenomenon. Gadamer, Heidegger and Merleau-Ponty on the other hand, claim that the attempt to "bracket" one's assumptions is ineffectual, giving only the false impression of objectivity. The object is not to set aside one's prejudices, but to work with and through them as part of the research endeavor. Recognition of prejudices allows the researcher to integrate them into the process. These become pre-understandings, integral to one's field of understanding: that which the researcher brings to the exploration. Ultimately, this may be the most important lesson we gain from bracketing: its final impossibility (Merleau-Ponty, 1962).

My own position regarding bracketing typifies a middle ground between philosophical extremes. In order to be more fully open to the descriptions of the participant's experiences of hope, I have found it helpful to know what it is I have brought to this research: my presuppositions and assumptions regarding hope. I have also been deliberate about keeping my own interests "in check" so that these do not overpower or corrupt the participant's descriptions of their experiences of hope. I have tried to "keep my eyes wide open" in order to "see" the phenomenon of hope. At the same time, I recognize that I have both affected the process and been affected by the research process-interpreting, filtering and assimilating what has been shared with me.

Hermeneutics

In Chapter One of Introduction to Philosophical Hermeneutics (1994), Jean Grondin states the following: "In present-day usage, the word *hermeneutic* is afflicted by a vast amorphousness. . .[which] may well explain why it has prospered. Such concepts as hermeneutic, interpretation, explication, exegesis are often used synonymously" (p. 18). Fundamentally,

hermeneutics is concerned with the "circularity of understanding" parts or specific elements of a text in relation to the whole.

Grondin (1994) describes two trends in the history of hermeneutics. First is the "prehistory" of hermeneutics, which he traces back through antiquity including Church history and ancient Greek philosophy. That history culminates with the emergence of "hermeneutics" in the seventeenth century. Hermeneutics is given specificity with Friederich Schleiermacher's (1868-1834) use of the word to convey both theory and method with regard to interpretation of scripture.

The second trend in the history of hermeneutics evolved from the first but results in "the more comprehensive form of a philosophy of phenomenology. . . which no longer teaches anyone how to interpret, but instead shows how interpretation is de facto practiced" (Grondin, 1994, p. 18). For Wilhelm Dilthy (1833-1911) Paul Ricoeur and Hans Georg Gadamer for example, hermeneutics involves a complex interpretive interaction between the 'subject' and 'object'. In other words, the meaning of any text is a function of the historical situations of both author and interpreter. Since each reading itself is grounded in its own context, no one reading offers a definitive or final interpretation of the text. This 'virtual dialogue' continues indefinitely.

It is Martin Heidegger who is credited with bringing hermeneutics to the forefront of phenomenological inquiry. Heidegger's concept of *Dasein* or "Be-ing in the world" gave an existential thrust to phenomenology with the concurrent emphasis on "understanding". For Heidegger, 'understanding' is not simply one manner of knowing but is instead a *mode of being*: a fundamental characteristic of our 'being' in the world (Koch, 1995). This study, as has been previously stated, takes a similar approach, and treats the descriptions of the experience of hope as "texts" in themselves, which through interpretation can illuminate our understanding of hope.

Hermeneutic Phenomenology

Hermeneutic phenomenology is a blending of description and interpretation. The melding of the terms itself may buttress each term's respective place as "ubiquitous feature(s) of the contemporary intellectual landscape" (Smith, 1987, p. 187). The use of the combined terms for this research however, is intentional and appropriate in delineating the specific "type" of inquiry, my attitude entering the study and the techniques chosen in proceeding with the study.

Van Manen, (1994) uses the terms interpretive, hermeneutics and phenomenology almost interchangeably, offering a simple definition of phenomenology: "phenomenology is the study of the world as we immediately experience it—pre-reflectively—rather than as we conceptualize, categorize or reflect on it (van Manen, 1994, p. 9). Before long however, the reader realizes that to *study* the world from a hermeneutic phenomenological perspective is to place oneself fully *in the world*, not standing apart from the phenomenon. Within hermeneutic phenomenology, one must remain true to that which is studied, as if Husserl himself were huddled in the background repeating his assertion *"to the things themselves!"* At the same time, the researcher must remain attentive to the insights and discernment process centering within the researcher herself and compounded by the ambiguity of language. Because language is always itself an 'interpretation', that is to say words are themselves overladen with meanings. Van Manen (1994) describes the process this way:

> To *do* hermeneutic phenomenology is to attempt to accomplish the impossible: to construct a full interpretive description of some aspect of the lifeworld, and yet to remain aware that lived life is always more complex than any explication of meaning can reveal. The phenomenological reduction teaches us that complete reduction is impossible, that full or final descriptions are unattainable (p. 18).

Hermeneutic phenomenology does not seek to explain, measure or quantify an experience but rather to bring to light for the reader a greater understanding of the "essence" of a particular human phenomenon, in this case, hope. It is descriptive and it is interpretive, offering insight into human

experience, perception, feeling and meaning in a way that appeals to the senses and experience of the reader.

This exploration of hope is phenomenological in that it seeks to describe the experience of hope for five women living with HIV/AIDS. Instead of universalising characteristics of hope and thereby potentially diminishing its meaning on a personal level, I first describe instead each woman's experience separately. The hermeneutic phenomenological exploration takes place separately, as the deeper meanings of the experiences are explored and presented. In this way, the particularities of each woman's experience of hope are highlighted and the hermeneutic phenomenological exploration moves through the circularity of interpretation to transform the lived experience of hope into a textual representation of its essential qualities (van Manen, 1994).

The Stream of Human Ecology

Human ecology is a continually evolving field, which studies the relationships between people and their environments. Human ecology seeks to address the complexity of human-environment relationships by affirming the interrelatedness of all things and the dynamism intrinsic to interactions within and across the contexts of daily living. Human ecology offers a holistic framework and a perspective that is fundamentally multi-faceted and interdisciplinary. Bubolz and Sontag (1988) suggest this definition of human ecology:

> From an interdisciplinary standpoint, human ecology can be defined as the study of humans as social, physical, biological beings in interaction with each other and with their physical, socio-cultural, aesthetic, and biological environments, and with the material and human resources of these environments. The uniqueness of human ecology lies in its focus on viewing humans and their near environments as integrated wholes, mutually influencing each other. (p. 3)

The ecological framework provides a way to conceptualize, discuss and evaluate the interdependent relationships between individuals and the multiple environments in which humans

both develop and live (Bubolz & Sontag, 1993). Having its roots in home economics and borrowing ecological concepts from the field of biology, human ecology has been used within a variety of disciplines. Concepts rooted in systems theory help to elaborate the framework, adding both dynamism and reciprocity as components of the human ecological framework.

As a perspective, human ecology is value-laden, and all encompassing. Human ecology is based upon a certain notable assumptions, three of which are discussed in the following sections: context; interactions, and outcomes.

Context

Fundamental to human ecology is the assumption that human beings do not develop or exist in isolation. Instead, we are part of a complex web of relational interaction with others, with the natural physical world and with our prevailing society and culture. These domains of interaction are the *contexts* for human development and human life. Within human ecology these contexts are typically referred to as 'environments' in deference to Bronfenbrenner's (1979) classic ecological model.

Bronfenbrenner's (1979) model offered the first systematic exposition of the ecological paradigm. In Bronfenbrenner's model, environments were depicted as a set of nested circles, representing hierarchical, successive levels. The three primary environmental levels were named as the micro-environment (family, peers, workplace), the exosystem (neighbourhood, city or town), and the macro-environment (the socio-cultural mileux). A forth, the meso-environment stood for the processes and interactions occurring *between* systems.

Another way to delineate human environments is to explain them as two types: the internal environment and the external environment (Westney, Brabble & Edwards, 1988). 'Internal environment' describes the psychosocial, mental and physiological processes that have a bearing on individual development; in other words, the inner resources of an individual while the external environments include the physical natural world, the social, economic, political and

cultural realities in which we live. External environments also included family configurations, work, or school. Regardless of terminology utilized, individual, 'internal' characteristics are recognized as a critical dimension of the ecological framework (Belsky, 1980; Bronfenbrenner, 1977, 1979; Bubolz & Sontag 1993; Westney, Brabble & Edwards, 1988).

The emphasis on context within human ecology has led to a special focus on families. The family is itself viewed as an ecosystem—an environment that is both embedded within, adapting to and mutually affecting multiple environments (Andrews, Bubolz & Paolucci, 1980; Bronfenbrenner, 1979; 1986; Hook & Paolucci, 1970). The family is seen as a "life-support system" for each family member. Likewise the family as a group is part of a physical and social interdependent whole:

> The family as a life support system is dependent upon the natural environment for physical sustenance and upon the social organizations which are related to [our] humanness and give quality and meaning to life. Home economists for some time have emphasized the social-emotional environment. It is necessary for the field (as it focuses on the family) to link both the natural environment and the social environment. Therein lie its uniqueness and strength (Hook & Paolucci, 1970, p. 326).

The family is seen as the vital link between individuals and their interactions within a larger socio-cultural framework. Concurrently, the family environment holds primary responsibility for socialization of individuals into society. Thus, the significance of the family as an ecosystem is a recurring theme in the literature and "family ecology" has become its own branch of human ecology in recent years (Bubolz & Sontag 1993).

The epidemic of HIV/AIDS, which this study examines, provides a good example of human ecology's concept of context as HIV/AIDS represents and brings with it a constellation of problems and issues. On a basic level one can assert that HIV/AIDS profoundly affects

individuals and families. Very quickly however it becomes clear that HIV/AIDS affects individuals *and* HIV/AIDS cannot be viewed separate from its social realities; the two dimensions are intertwined. A woman living with HIV/AIDS deals with her disease on a multiplicity of levels: from the personal interactions with family and friends to the possible impact of public policies regarding treatment protocols and access to medical care. Through the course of her disease she will interact with many environments: the near-environment of her family and loved ones, the health care setting, her place of work or school environment, government and social agencies which offer support services, and the culture within which she is living. The physical manifestations of HIV disease and her emotional responses to HIV take place as part of her internal environment, interdependent with her interactions among the varying contexts of her daily living.

Interactions

By itself, the concept of 'environments' within human ecology might appear to present a static conceptualization. But the second assumption of human ecology *integrated into* descriptions of the multiple environments is the premise of the interactive components within and between environments. The combination of the concepts of environments and interactions adds dynamism to the human ecologic framework.

Integral to human ecology is the presumption of the *interdependence* of all environments; that is, humans are understood as part of their environments, not separate from them. Humans affect and are affected by the dynamic and reciprocal exchanges that occur when interacting within and across the various environments, or domains within which humans exist. These interactions contribute in a multiplicity of ways to personal, interpersonal, and social formation.

Human ecology has adapted concepts related to systems theory in order to describe the interactions occurring within and between environments. Ideas such as 'transactions', 'input', and 'throughput' are utilized in conjunction with terms borrowed from the biological sciences, such

as, adaptation, entropy, and homeostasis. The processes by which individuals interact within (and between) their environments is called adaptation and is marked both by change and stability. The processes of adaptation and interaction are intertwined in an ecological understanding. Bronfenbrenner's (1979) definition of an ecology of human development conveys the point, using the words 'accommodation' and 'context': "[An ecology of human development] is the scientific study of the progressive, mutual accommodation between the developing person and the changing properties of the immediate and broader contexts in which the person lives" (Bronfenbrenner, 1979, p. 21).

One underlying assumption of mine is that interactions within (and among) the varied environments have a bearing on individual experiences of hope. The context of each woman's life, her interactions with others (including care and service providers, health care professionals, co-workers, and friends), and her capacity to adapt to the changing circumstances of HIV/AIDS inform her experience of hope. Hope may be depleted or enhanced, confirmed or dashed, as each woman interacts with and lives within her various environments. Understanding interactive nature of individuals between and within their environments has been an underlying assumption of this research as it explores the experience of hope for women living with HIV/AIDS.

Outcomes

The third assumption of human ecology important to this study is that of 'outcomes'. The interactions between individuals and their environments, taking place within multiple domains impact the environments and results in modification or changes, typically referred to as 'outcomes.' Systems are constantly in a state of flux, changing and seeking balance both internally and externally. Bubolz and Sontag (1993) emphasize learning as an outcome of the process and an essential part of adaptation (change) itself:

> Adaptation is behavior of living systems(e.g., the family) that changes the state or structure of the system, the environment, or both. Humans do not simply adapt to the

> environment but also modify the environment to reach desired outcomes. Adaptation is a necessary process for the growth and progressive integration of living systems. Learning is an essential part of this process (p. 433).

The assumption of interdependency permeates an ecological perspective (interdependency of parts to the whole) and has brought to human ecology a focus on values. That is, the well-being of individuals and families cannot be considered apart from the well-being of the environment; environmental quality and human quality of life are interdependent. Citing Capra's (1982) contrast between 'eco-action' and 'ego-action,' Bubolz and Sontag (1993) claim the following:

> The underlying moral value structure of human ecology is grounded in a balance between demands of the ecosystem for cooperation and integration and demands of the individual for autonomy and freedom. A dynamic interplay between these two complementary tendencies is necessary to maintain both a viable, orderly system and the capacity for change. Moral judgments and actions of individuals and families must take this complementarity into account. Ideally, universal values that stand in service to the common good of the global ecosystem should be congruent with the values of individuals, families, and other groups (p. 425).

Because of the mutual reciprocity between humans and their environments, human ecology brings to light values such as survival, human betterment, justice, and quality of life. These 'outcomes' of human interactions may appear grandiose, but they are at the heart of the ecological framework. By placing individual actions in the causal matrix of ecosystem dynamics, focus is placed on human agency and the consequences of human action. Just as a ripple in a pond will move ever outward, individual actions have their effects across (and between) environments. If a corporation dumps toxic waste into the air or water, people, animals and plants in the near and far vicinity will feel the effects. On a smaller scale, family decision-making

(regarding consumption of goods or recycling for example) must take into account the effects of their actions in other spheres: socially, economically, and in relation to the physical environment. An ecological ethic addresses this interplay of humans with all of their environments.

The ethical dimension offered by an ecological framework is important to discussions about HIV/AIDS. As a holistic interrelated framework, human ecology assumes that what happens to one part has ramifications for the entire ecosystem. Thus, marginalization of some members of society will necessarily impact the rest of society. When individuals have equal access to health care, medications, and treatment options then it is clear that the system is working for the good of all. Moreover, HIV/AIDS has pointed out political and social shortcomings across the systems, raising issues of justice and fairness while asserting the necessity for an integrated understanding of human living.

The Stream of Feminism

Feminism simply defined is the call for social, political, economic, and intellectual change based on the assertion that women and men are equal. It assumes that the social, political, economic, and intellectual environments are androcentric, that is, shaped and influenced by a male perspective and the presumption of 'maleness' as the norm (Eichler, 1988; Hooyman & Gonyea, 1995).

The above definition notwithstanding, 'feminism' is a diverse, broad and evolving framework, which cannot be characterized as one monolithic perspective; rather, it is best described as one stream with many tributaries! Feminist perspectives range from liberal to socialist to radical to postmodern. Consequently, feminism has been described as a *diversity of representations*, a 'family' of theories in which the various members of that family often disagree on philosophy and strategies (Campbell & Bunting, 1991). Within feminism can be found a variety of fields for example, feminist epistemology, feminist history, feminist literary criticism, feminist political theory, and feminist theology. Feminism also addresses human sexualities,

ethnic diversity, human physiology and the environment. These lists are by no means exhaustive. In fact, it is common for feminist theorists to identify a particular perspective through the use of hyphenation in order to delineate the perspective further (i.e. Marxist-feminist; eco-feminist). Indeed, one risks *under*-representing the varying and ongoing debates by not specifying a particular perspective within the wide-ranging feminist framework.

Feminism, then, encompasses a diversity of representations and a comprehensive description of each of them goes well beyond the scope of this project. Nevertheless, three theoretical concepts commonly associated with feminism are presented along with their relevance to this study: the centrality of gender; the affirmation of diversity; and the imperative for social change.

Gender

The theoretical concept of gender is more accurately described as two intertwined themes within feminist theory: the centrality of gender and women's engendered roles. Feminists have long asserted the centrality of gender. Judith Grant (1993) critiques what she names as the three core concepts of feminism, foremost being the concept of "woman". Osmond and Thorne (1993) maintain that among feminisms, gender is not one variable among many but *is itself* a basic theoretical concept, "the starting point for analyzing personal, interpersonal, social and political dynamics; indeed for understanding the world" (Osmond & Thorne, 1993, p. 592). A vast array of feminist literature asserts the centrality of gender even while reflecting a wide range of theoretical standpoints with regards to the definition and meaning of gender. These positions can be categorized under three headings:

1. The equality position, which asserts that fundamentally women are no different than men and (therefore) should be accorded equal standing in all facets of society (Friedan, 1963)
2. The essentialist position represented by the assertion that women are different than men, displaying different characteristic traits such as care and concern for others. Traits are rooted in the biological differences, in particular women's capacity for childbirth and mothering (e.g. Nancy Chodorow, 1978; Sara Ruddick, 1989; Carol Gilligan, 1982).

3. The poststructuralist and postmodern positions which challenge the underlying assumptions occurring in the creation of language and meaning (for example Judith Butler, 1990; Helene Cixous, 1976; Luce Irigary, 1985)

The first category is represented by the 'second wave' of feminism of the twentieth century and the proliferation of feminist literature calling for equality. Referred to now as 'liberal feminism', the demands centre around equal rights such as pay equity for men and women and equal access to employment. The problem with the equality position is that it necessarily privileges 'gender' above and beyond class, race and other cultural identities.

Essentialist arguments as described in item two minimize differences between women by attributing inherent traits to all (women and men). Essentialism is a strong thread running through the feminist literature even though essentialism reflects dualistic thinking and a reiterates categories of gender that feminists have sought to overcome (Diquinzio, 1993). Although running the risk of sliding into relativism, postmodernism embraces the ambivalence, paradox, and heterogeneity of women and gender discussions with its claims regarding multiple truths, multiple roles, and multiple realities. Postmodern feminism provides a way to "understand and construct the self, gender, knowledge, social relations, and culture without resorting to linear, teleological, hierarchical, holistic, or binary ways of thinking and being" (Flax, 1987, p. 622). Instead, a postmodern feminist approach questions the nature of knowledge and the structures undergirding human interaction.

The feminist assumptions I bring to this research regarding gender are twofold. First, that sex is biologically rooted while gender is socially created. 'Sex' comprises the biological differences between males and females, while gender is *relational*, not a biologic 'given'. In other words, 'gender', (that which is labeled masculine or feminine) is not "a rigid analytic category imposed on human experience reflecting immutable differences, but a fluid one" (Hooyman & Gonyea, 1995, p. 26). Gender is what societies *make* of the sexual differences the different roles, norms and meanings assigned to men and women. Gender is not only a social construct, created

and recreated through our interactions and social systems but also becomes symbolic of the differentiation between men and women that has become deeply ingrained in the structures, culture, and belief systems of western society (Hooyman & Gonyea, 1995; Patton, 1994). Another assumption I bring to this endeavour stemming from this discussion is that gender-based inequality is fundamentally wrong and ultimately harms both men and women.

Gender inequality, gender role formation and gender politics have been crystallized in "AIDS" since the beginning of the epidemic. During the first decade of HIV/AIDS in the United States, women were virtually ignored, despite the fact that women were known to have been infected with HIV (Correa, 1992; Shilts, 1988; Travers & Bennett, 1996). Prevention education messages were geared toward men. Women were excluded from early drug trials and the scientific community was slow to respond to demands for gender-specific research (Berer & Ray, 1993). During that first decade as well, gynecological manifestations of HIV infection frequently went unnoticed by physicians and women could not access AIDS care and services until well into the second decade of HIV/AIDS (Coward, 1994; King, 1994).

Cindy Patton (1994,1990), Linda Singer (1994), Susan Sontag (1988), and others have analyzed the AIDS epidemic as a viral epidemic layered with socially constructed meanings. These authors, and others, have laid bare the ways in which culturally ingrained gender-based stereotypes about men and women, myths about contagion and the devaluation of women coalesced in three important ways. First in the initial depiction of AIDS as a gay disease and, secondly, the (consequent) slow response to the epidemic. The third outcome was the refusal to recognize women's needs in the epidemic. During the first decade, research related to women focused on the infection of children during pregnancy, pediatric HIV/AIDS and the transmission of HIV via sex workers while the emotional and physical effects of HIV/AIDS on women in general were neglected. Women had been virtually excluded from research studies examining the

particular psycho-social issues of *women* living with HIV/AIDS, women and caregiving, women's sexual behaviours and attitudes (Coward, 1994; King, 1994; Squire, 1993).

Feminist authors have raised another gender-related issue within the AIDS epidemic, and that is how women have been defined through popular culture. Because of its association with drug use and sex, the prevailing social descriptions of AIDS among women followed two predominant trends: women with HIV were characterized as either promiscuous or as vectors of transmission. As promiscuous, women were portrayed as either having brought it on themselves or as vectors of transmission (through prostitution or childbirth) women were therefore a threat to "the rest of society" (Carovano, 1991; Scharf & Toole, 1992; Singer, MacGrogan and Butler, 1993).

An equally strong trend in media portrayals of women and HIV was the portrayal of (some) women as "innocent victims." Women who became infected with HIV through blood transfusions were treated much differently than those who became infected through sexual or drug using behaviors. These contrasting good-girl, bad-girl images of women reflected deeply ingrained stereotypes of women and implied judgment on women's behavior and choices (Carovano, 1991; Scharf and Toole, 1992; Schneider and Stoller, 1995; Singer, MacGrogan and Butler, 1993; Sontag, 1988).

My own experience confirms these theories about gender and women's engendered roles. Most of the women who attended the support group in 1995 had known little about HIV before they became infected, even though HIV had been firmly established as an epidemic in the United States. Believing HIV to be a "gay disease" most of the women themselves did not realize they were at risk when having unprotected sex or sharing needles. Many of the women had repeatedly questioned their physicians about HIV only to be given responses reflecting the media stereotypes. Comments such as, "Why do you need an HIV test, what have *you* been doing" and, "Women like you don't get AIDS' were heard all too frequently, dismissing women's legitimate

concerns. Similarly, many women I counseled had been symptomatic for months, and in some cases years, before their physicians took notice.

The women often reacted similarly to seropositive test results: with feelings of shame and self-loathing (*I feel so dirty*); feelings of loss over potential relationships (*What man will want me now that I have HIV?*); feelings of failure toward children (*What will happen to them when I have died?*); and feelings of loss, or fear regarding potential pregnancy. Moreover, even though attending a support group for themselves, it was often difficult for each women to articulate thoughts and feelings related to *her own* health, *her own* personal struggles, *her own* fears and dreams, worries and hopes. Typically the women spoke first about partners, children, or extended family members. A feminist perspective now allows me to more fully understand the extent to which these women defined themselves, viewed themselves and discovered their self-worth (only) in relation to another person—generally a man or a child.

The example from those early days of the women's support group highlights two intertwined themes within feminist theory: the centrality of gender and women's engendered roles. These interwoven themes have informed my understanding of HIV/AIDS as a women's issue and form the basis for the intentional emphasis of this study on women and women's experiences.

Diversity

Acknowledging the centrality of gender is one dimension of feminism. A second area of theoretical import to this study has been the feminist assertion of difference. Feminism has brought to light the fact that gender is important in and of itself and it is important *in relation to* other differences and inequalities. Feminism is concerned with the complex interplay of relationships between gender and the paralleling realities of race, ethnicity, class, religion, sexualities, age and abilities. Thus, the feminist focus on gender merely highlights one (albeit important) form of difference—the difference between men and women. The assertion of

"difference" as a second theoretical concept seeks to address the diversity *among* women themselves.

Emerging from a critique of the feminism of the 1960's and 1970's in the U.S. as white and elitist, feminist theorists of the eighties and nineties have highlighted the varying experiences of women of colour, lesbian women and poor women. Feminists such as Audre Lorde (1981; 1983), Angela Davis (1981) and bell hooks (1981; 1984) have brought to light the racism inherent in the white women's movement and paving the way for debate regarding the intersection of race, class and culture:

> In different ways [feminist authors] have pointed out the problems faced by feminism in constructing a universal feminism: in just the same way as the male and masculinity was de-constructed as the universal norm, so feminism has to be de-constructed to allow for difference and diversity between women, quite as much as between women and men. The two words 'difference' and 'diversity' have thus become synonymous with feminism in the 1990's (Evans, 1997, p. 62-63).

As has already been pointed out, within feminist theory there is a wide range of political affiliations, fields of interest and perspectives. The multiple voices of women heard within feminism and the appreciation for diversity have contributed to a healthy intellectual ferment in feminist theory (Harding, 1987), while nevertheless presenting challenges to forging feminist solidarity:

> Women are not a homogenous group. Speaking of them as though they are obscures the richness of their thinking, experiences, and contributions and oppresses women who are not allowed to speak in their own voices . . .there is no *woman's* voice, no *woman's* story, but rather a multitude of voices that sometimes speak together but often must speak separately. What is oppressive for one group of women may not be perceived as

> oppressive by another group; what is meaningful and salient for some may not be for others (Baber & Allen, 1992, p. 19).

Even when numbering only a few, the women's support group was racially and culturally eclectic, made up of African American, Latina and Caucasian women from a variety of life's circumstances. There were other differences among the women, such as differences in ages, sexual experiences, experiences with violence, racial discrimination or abuse. Some of the women fought addiction; some were poor. Some of the women spoke English only as a second language. Some women had children of their own. Some of the women were overtly religious and some were more highly educated than were others in the group.

As I listened to these women, I frequently reflected upon both the differences within the group and the similarities among the circle of women. The issues affecting the women in the support group overlapped and intersected. Still, they could not be generalized to affect "all women" or even "all women with HIV/AIDS". These issues of universality and diversity speak to what Lorraine Code (1993) calls "the paradox at the center of feminist theory in the 1990's. Referencing another feminist author (Nancy Cott, 1986), Code states, "ethnic, racial and sexual diversity among women is stressed more than ever before in feminist theory, *but so is* the emphasis on how women (as a whole) differ from men (as a whole)" (Code, 1993, p. 48 emphasis mine).

Because so many of the issues at the heart of these women's experiences are gender-based, I can say without hesitation that their experiences differ dramatically from those of the vast majority of men who live with HIV/AIDS. At the same time, this research is rooted in the unique experiences of each of the five participants. I have neither tried to amalgamate their stories nor make sweeping generalizations from their experiences that pertain to all women.

Social Change

The third area of theoretical import is feminism's commitment to social change. As Linda Rennie Forcey so aptly puts it, "[Feminism] is both a way of viewing the world, and an evolving social movement" (Forcey, 1994, p. 358). Gender has been the centerpiece of social analysis leading feminism to analyze and critique the ways in which social structures have historically and systematically excluded women from holding political and economic power. At the heart of feminism is the belief that inequality in all forms is fundamentally wrong. Thus, feminism is a *movement* that seeks social and political change: "[this implies] that one must be engaged with the government and law, as well as social practices and beliefs. And implicit to these goals is access to sufficient information to enable women to make responsible choices" (Baumgardner & Richards, 2000).

As highlighted in Chapter One of this dissertation, recognition of women's needs and women's issues regarding HIV/AIDS was slow in coming. The melding of the feminist movement and gay liberation movements helped forge coalitions in response to HIV/AIDS and helped foster social change. It was the vision of social justice and social change, combined with pressure on governmental agencies, research establishments and social institutions which helped bring attention to women's issues and women's needs regarding HIV/AIDS.

The Confluence

The confluence is a merger point—a place of excitement and turmoil as things become stirred up and mixed around. What emerges from the confluence is something new: a melding of streams to form a (new) river which itself carries on, contributing to and being affected by many natural and human-built encumbrances. When one experiences a river and the oceans into which all rivers flow, it is easy to forget all the tiny streams, creeks, drops of water and snowflakes contributing to the fullness of the larger picture. So it is with this project. It is not my intent to analyze the experience of hope *specifically* from either an ecological, feminist or philosophical

perspective. Instead, this study is a more subtle reflection of each of these three modes of inquiry, marking my orientation and pre-understandings as well as highlighting epistemological and methodological issues.

I have chosen to explore hope among women with HIV/AIDS. This is a personal choice emerging from the fact that women's experiences in the AIDS pandemic have been undervalued and generally excluded from the research. This choice is rooted in my own feminism, seeking both to align myself with women's struggles and to change the deeply engrained social structures of sexism, racism and homophobia, which coalesce around HIV/AIDS.

Social issues related to gender (violence, empowerment and self-esteem) and the failure of biomedical medicine to broaden its analysis of the HIV epidemic have contributed to placing women at risk for HIV infection. Concurrently, the dynamics of gender have contributed to creating the context within women's identities are defined (as mother, partner, daughter, etc.), the choices available to women and to the context within which women's experiences are lived. Gender is significant in understanding the life context of each of the participants. Rather than competing with either phenomenology or human ecology, a feminist perspective highlights and illuminates questions pertaining to women which neither human ecology nor phenomenology specifically address. For example in what ways are gender-based realities intertwined with (these) women's experiences of hope?

The human ecological perspective requires the contextualization of this research. It has been important for me to place this study in historical context while situating it within my own experiences with HIV/AIDS while living in the United States. Although it is beyond the scope of this research to do contextual *analysis* of each woman's interactions between or within her environments, the human ecological perspective acknowledges the importance of these and provides justification for including personal descriptions of each participant. By so doing, the reader can place each participant's comments in the context of what is known about her life: her

support systems; her living space; her work or school environment; the policies and priorities of life in this part of the United States; her place in the natural-physical world.

While introducing a discussion about phenomenology, Tina Koch (1996) warns "[that] these amorphous philosophical areas are a potential minefield and guidance from an experienced scholar familiar with them is required (p. 175)". Given the focus of this study (the experience of hope among women with HIV/AIDS), and my perspective as a feminist and human ecologist, this 'potential minefield' has for me instead become a goldmine. Hermeneutic phenomenology offers a blend of specificity with the nuances of interpretation and freedom in methods that fits perfectly within the theoretic foundations of both the human ecological and feminist perspectives. Acknowledging the inter-subjective creation of meaning, the issues regarding language derivation and usage, the interaction of parts to the whole (individual within society), and the emphasis on reflexivity are but some of the concepts common to the three streams of thought. The three streams of human ecology, feminism and hermeneutic phenomenology merge and together form the ontological, epistemological and methodological suppositions of the research.

A confluence is not always tidy but it can be powerful. My experience in merging feminism, human ecology and phenomenology can be likened to a white water ride down each separate stream. Sometimes I have felt overwhelmed, swept away by the power of each stream. At other times I have felt exhilarated as I caught glimpses of the confluence and wondered what indeed would emerge from the joining. At still other times I simply enjoyed the journey—hanging on and moving along with those feminists, human ecologists, phenomenologists and others who are moving within and between the streams, feeling the need to move beyond the debates, " . . .with a finely tuned appreciation of a variety of approaches, a tolerance for ambiguity, and more than a little theoretical untidiness" (Forcey, 1994, p. 357).

CHAPTER FOUR

METHODOLOGY

Writing a methodology chapter for a hermeneutic phenomenological exploration such as this presents an interesting conundrum since among the broad range of phenomenologists exist the extremes of commitment to 'method'. On the one hand, some phenomenological studies are undertaken utilizing specific steps and procedures (Colaizzi, 1978; Giorgi, 1985; Polkinghorne, 1989) while other phenomenologists eschew "method for method's sake" (Bergum, 1991; van Manen, 1994). This study adheres closely to van Manen's (1994) broad methodological framework, which allows for fluidity and personalization of the research process while demanding rigorous commitment to hermeneutics and phenomenology.

This study is a hermeneutic phenomenological exploration of the experience of hope among women who are HIV infected. The following two questions are integrated: first, what is the experience of hope *like* for the participants in this study and secondly, what is the meaning of the experience of hope for each of these women? In this chapter I will explain the research process first in a general way and then by explicating the specifics of this hermeneutic phenomenological exploration of hope among women with HIV/AIDS.

The intent of hermeneutic phenomenology is to keep in balance, like a finely tuned scale, two equally important dimensions of inquiry: *description of the experience* (the phenomenological dimension) and *interpretation of the meaning of the experience* (the hermeneutic dimension). In this study, the phenomenological side of the scale calls for description: to depict for the reader what the experience of hope is *like* for each of the participants. The hermeneutic dimension (the other side of the scale) broadens the description attempting to understand, interpret and convey the *meaning* of the experience.

The methods used for data collection were chosen to help maintain the balance between description and interpretation. Photography, journal submissions and individual conversations

with the participants were used to gather descriptions of the experience of hope. My own journal entries and field notes, intense, repeated reflection on the gathered data, and reflection upon outside materials such as literature, poetry and art contributed to the hermeneutic endeavor. What follows is a description of the research process. The rationale determining the choices for data collection and the procedures for implementation of the methods is described in detail.

Doing Hermeneutic Phenomenology

With its emphasis on experience and meanings associated with the life world of individuals, hermeneutic phenomenology offers a research strategy that is appropriate for this research. In other words, the method ought to serve the 'question' or goal of the research, which is in this case, is to understand the meaning and experience of hope (Field & Morse, 1991). However, aligning myself with this form of inquiry does not necessarily provide a strict set of methodological guidelines, as the *doing* of hermeneutic phenomenology is neither linear nor tidy. Still, this form of research demands a disciplined, integrative process. The process includes gathering descriptions about the topic, reflecting on the gathered data (as well as other pertinent materials) while attempting to portray through the written text the meanings embedded within the descriptions of the phenomena. All of this is to take place without losing the concreteness of the description.

Van Manen (1994) offers a methodological structure for pursuing hermeneutic phenomenological studies that has provided a meaningful guide to the research process undertaken in this study. The structure is portrayed as a dynamic interplay among six interrelated research activities (p. 30):

1. Turning to a phenomenon which seriously interests us and commits us to the world;
2. Investigating experience as we live it rather than as we conceptualize it
3. Reflecting on the essential themes which characterize the phenomenon;
4. Describing the phenomenon through the art of writing and rewriting;
5. Maintaining a strong and oriented pedagogical relation to the phenomenon;
6. Balancing the research context by considering parts and whole.

As listed, these six *in themselves* present nothing new, as most qualitative research involves one or more of the aforementioned research activities. For example, it could be argued that all research is prompted by a concern of the researcher – who turns to a phenomenon of serious interest (van Manen's number 1); otherwise, why would a researcher "do" research in the first place? Likewise, all qualitative research demands maintaining a strong orientation to the question (van Manen's number 5) and balancing the research context by considering parts to the whole (van Manen's number 6). The operative phrase governing van Manen's schema is "dynamic interplay". It is the "dynamic interplay" of the six research activities, which gives life and complexity to hermeneutic phenomenological inquiry.

Without the dynamism and interrelated character of each activity to the other pieces of the schema, the six research activities become little more than somewhat obvious statements, essential components of most qualitative research endeavors. The crux, creativity and genius of hermeneutic phenomenology lies specifically in the "dynamic interplay" of van Manen's items 2, 3, and 4: investigating experience as we live it rather than as we conceptualize it; reflecting on essential themes which characterize the phenomenon; and describing the phenomenon through the art of writing and rewriting. At the outset of this investigation, I had not fully recognized how truly integrated were these activities; the layering of these activities and their integrated character was made clearer for me only as I became immersed in the research process.

Van Manen's schema provided the framework for this study. However, I took some liberty with his concepts by renaming them in a way that helped me to better understand their interrelated, integrated character. For example, phenomenological "investigating" (van Manen's number 2) became clearer when renamed *probing with curiosity*. The word *curiosity* captures the openness (phenomenological attitude) with which I had hoped to approach the study and the topic of hope among the participants. The term *probing* accentuates the character of phenomenological inquiry: seeking ways that might bring forth the richest possible descriptions of what the

experience [of hope] is like and relentlessly searching for ways to describe and illuminate the phenomenon.

In order to convey the subjective dimension of the research process, I renamed the reflection dimension of this phenomenological exploration (van Manen's number 3) *contemplative mirroring*. The word *contemplative* addresses the fullness of thought – the thoughtfulness – of the reflective process. The term also gives emphasis to the fact that everything is sifted through the researcher, in this case, me. Throughout this past year I literally became obsessed with the experience of hope as described to me by the participants. I thought deeply and often about their descriptions, the differences and similarities of their experiences of hope – the words and turns of phrase used by the women to convey their experiences. I reviewed the transcripts and listened again and again to the tapes, continually pondering what I had heard and intuited from the participants. I listened for recurring words or phrases while staying attentive to the silences and the nuance of expression. Becoming a 'contemplative' of hope also meant sifting through what I had heard from the participants in relation to other studies and explorations of hope, and in relation to my own experiences of hope.

The term *mirroring* is paired with the term *contemplative* to more accurately convey the ongoing nature of the reflective process. As a child, I was fascinated by a three sided mirror built as part of a vanity in the washroom at my father's office. Sitting on the counter I could see my reflection multiplied (it seemed) a thousand times – more of myself and more angles than I could imagine; the images just went on forever! Like mirrors reflecting back on themselves, so too the contemplative/reflective mirroring process became ongoing, integrated throughout the research process.

A general example from this research can illuminate what is meant by *contemplative mirroring*. One participant seemed to use the word 'strength' interchangeably with the word hope. This prompted a number a number of questions, which I both contemplated and explored

with the participant herself. For instance, when the participant said 'strength' I wondered whether she meant inner strength or strength-related to physical capabilities? Did having strength mean that she believed she could beat (as in beat up or be stronger than) the HIV? Or did feel she could hold on (with strength/hope) regardless of what she faced? While she might use the words interchangeably, it was important to explore whether her *experience* of 'strength' was similar or different from her experience of 'hope'. Consequently, along with the word hope, I explored the meanings of the word strength – how had been used elsewhere, its etymology and definitions and how the layers of meaning overlap and coalesce with the various meanings ascribed to the word hope.

The dynamic interplay of van Manen's three central research activities (number s 2, 3 and 4) is brought to the fore as one enters into the process of writing and re-writing. In a hermeneutic phenomenological inquiry such as this, the process of writing is ongoing, recursive and fosters a deep reflection on the topic. As one attempts to convey a description of the phenomenon through writing, one sees and experiences how that description is or is not effective. The description is tested out on the page and the written words stand or fall in relation to what one is trying to describe. Thus the researcher is called to begin (and begin again) trying different configurations, varying the words, choosing and deleting descriptive phrases in order to most accurately and appropriately portray the phenomenon for the reader. The activity of writing, then, is interconnected and in dynamic interplay with other dimensions of the research process.

Another helpful way to portray the interconnected character of the phenomenological research process would be to delineate the activities as follows: *investigating... investigating reflecting ... investigating/reflecting/ writing.* Rather than implying that there is a step by step linear progression to hermeneutic phenomenological research, the slashes and repetition depicts visually the way in which each research activity builds upon and incorporates the other.

In order to describe the processes utilized in this phenomenological exploration of hope, I will use as a guide van Manen's research activities with the elaborations previously noted.

Turning To A Phenomenon With Interest and Commitment

Having lived in the United States for most of my life, I have seen the evolution of the HIV/AIDS from its first emergence as a curious medical anomaly among gay men to becoming a world-wide pandemic. I have also felt its effects personally over the years as friends and those I worked with became ill and many died. Having worked for two AIDS agencies over the course of seven years, I have had varied and extensive experience with many facets of the epidemic including hands-on caring work for individuals with HIV/AIDS and their loved ones.

As explained in detail in Chapter One of this dissertation, I became interested in the dynamics of hope as experienced by women who live with HIV/AIDS. A women's support group at the AIDS Services Centre (ASC) became a source of hope and a place where hope was shared among the women. My interest in this study initially arose from these personal experiences with people who are HIV positive. The pairing of hope and the context of HIV/AIDS seemed a natural pairing as "the phenomenon which seriously interests me and commits me to the world."

Research Site

Support from the AIDS Services Center in Bethlehem, Pennsylvania (USA) was secured before proceeding with the investigation. ASC is a non-profit service organization serving those individuals living with HIV or AIDS who live within an area spanning three counties in South-eastern Pennsylvania. Because of its ethnic diversity and its locale near three metropolitan areas reporting among highest number of cumulative AIDS cases in the United States (Philadelphia, Pennsylvania, Newark, New Jersey and New York City, New York), south-eastern Pennsylvania is an area of the United States with high rates of HIV infection—particularly among women (CDC, 2000). ASC provides case management, health promotion and HIV/AIDS prevention information, social opportunities and support services (e.g., counselling, support groups,

referrals), for clients of mixed race and ethnicity. Anyone who is HIV positive may access the services of ASC free of charge.

The site was originally chosen because of the cultural and ethnic diversity of its clients and because of my familiarity with the organization. Having worked at ASC as co-ordinator of the women and children's program prior to my doctoral studies, I also had the connections within the agency both for approval of the project and access to potential participants. ASC's executive director gave permission for agency involvement in the study while the case manager for the women's program at ASC agreed to help solicit volunteers for the sampling interviews (the letter of agreement with the agency can be found in Appendix A).

Participants

Purposive sampling was utilized through the AIDS Services Center's Tuesday evening women's support group. In order to gather rich and diverse descriptions of the experience of hope, I wished to secure a heterogeneous sample, knowing this might call for secondary sampling (e.g. snowball) to ensure diversity (Morse, 1991, 1994). It was my intention to interview and choose six women to participate from those who would volunteer for the study. The following inclusion/exclusion criteria served as the primary guide:

1) Female client of AIDS Services Center (confirming HIV status)
2) The ability to communicate in English
3) Willingness to participate (insofar as she wished and as her health allowed in the activities of the project: personal conversations, journal writing, and photography.

A flier was posted at the agency and a verbal announcement was made to the women's support group by the facilitator (see Appendix B). After the announcement at the support group, four women volunteered for the study. One woman responded to the posted announcement by contacting her case-manager and voicing an interest in participating. Another woman was recruited by one of the four women from the support group. I was given phone numbers for all of these women and proceeded to contact them. Contact was made with five of the six volunteers. I was unable to reach the sixth woman and consequently decided to proceed with the five.

Because ASC is cross-cultural, potentially the sample could include Hispanic, African-American and/or Caucasian participants. Because phenomenological exploration is not dependent upon diversity, I chose not to include ethnicity as sampling criteria. Two African-American and three Caucasian women volunteered for the study. Consequently, the sample in this study was not representative of the racial demographics of HIV/AIDS in the United States, where African Americans and Hispanic women are disproportionately affected by HIV/AIDS (Goldstein & Manlowe, 1997; Lather & Smithies, 1997). However, each woman was eager to volunteer, as if she wanted her story to be told, and her voice to be heard.

Investigating The Lived Experience of Hope: (Probing With Curiosity)

One of the assumptions guiding the research design of this project was the assumption that, because it is deeply personal, hope may not be an easy topic about which the participants could talk. With this in mind, I consciously chose three different ways of communicating (speaking, writing and the use of images) in the attempt to better access the experience of hope. The investigation component of this study, then, involved three primary methods of data collection: (1) individual conversations with the participants (2) journal submissions and (3) photography.

The data collection took place during four visits to the United States over a nine month time period between November 1998 and August of 1999. My first contact with each person was made by phone after volunteers came forward following the recruitment announcement made at the women's support group. During the phone conversation, the project was explained in detail and the informed consent form was read to the volunteer. At that time an appointment was made to meet with each volunteer at her home at her convenience. The initial meeting included an overview of the project, securing written informed consent, and a first conversation about the experience of hope. Subsequent conversations were guided by my analysis of previous conversations, the women's journal submissions and the photos.

My proposed schedule was to have a minimum of three separate conversations with each participant over a three-month time period. Between November of 1998 and March of 1999, I had been able only to secure two conversations with three of the participants, three conversations with one of the women and only one conversation with the fifth participant. Although I was pleased with the content of the conversations, this change in scheduling the research underscores one of the challenges of long distance research with participants living with acute illness.

Because of the long distance nature of this project, it was critical that everything go as planned while I was on site in Pennsylvania, usually for a week at a time. The reality was that the logistics were cumbersome. Each participant faced life's complexities, not the least of which was her health concerns. At times his made it difficult to meet with all of the women within my time constraints. One woman, for example, could not be contacted because she was seeking safety from an abusive boyfriend. Another woman abruptly cancelled a pre-arranged meeting taking advantage of an unexpected offer to go to the shore for a few days.

Ultimately four of the five participants were able to complete the project in its entirety. The fifth participant left town abruptly in the spring of 1999. Her health and her whereabouts were unknown to me, to her case manager or to any of her friends. I was able to meet with the fifth participant only once; nevertheless, her experiences of hope have been included as a part of the discussion.

In spite of the logistical problems stated above, the selected methods were effective in gathering ample information about the women and rich descriptions of their experiences of hope.

Conversations

The primary source for information about each participant's experience of hope was drawn from individual conversations. Conversation rather than interview was chosen intentionally as a method for gathering women's stories regarding their experiences of hope. There is a back and forth quality about conversation, which is much more natural than a formal interview. The

conversations were open ended and casual, building upon a sense of trust established at the outset. The conversational back and forth put both the participants and myself at ease, which facilitated deepened sharing about many topics related to hope (and HIV/AIDS) and increased openness about the topic of hope (Bergum, 1989; Coliazzi, 1978; Kvale, 1983).

Kvale (1983) describes a conversation as part of the construction of knowledge that comes from "a dialogue between two partners about a topic of interest" (p. 42). For Gadamer (1994), a conversation is "a process of coming to an understanding" (p. 385). Each conversation with the women was indeed a process, unfolding as conversations do: at times light, at times intense with twists and turns as we discussed hope among (and in the midst of) other topics. For example, one conversation with a participant began with me talk about the recent death of her brother and other family stresses. Hope wasn't mentioned [illegible] into the conversation, when I asked whether she had experienced hope through those recent experiences of stress and loss, and what that experience of hope was like. In this way, although my role as researcher was never hidden, I made every attempt to put the participant at ease and to enter into the topic of hope in a natural way, during the course of the conversation.

During each conversation, my intent was to keep focused on the phenomenological dimension of hope by seeking varied descriptions of the experience of hope and by continually probing what the experience was like. Each participant was asked to describe for me a time when she experienced hope, to tell me in story form about what happened. Each time I explored further with her what that experience felt like, asking questions to bring forth as much description as possible. Most of the questions were open-ended and allowed space for the participant to access her own words and images to convey her thoughts. I listened attentively and actively, clarifying when necessary and paraphrasing her responses throughout the conversation (Kvale, 1983). Descriptions and meanings gleaned from the first conversations informed subsequent conversations. Three conversations were attempted with each participant. The intent for the

second and third conversations was threefold: to clarify earlier conversations; to discuss the photographs and to engage in conversation regarding any journal entries. Engaging in multiple conversations with the participants created what Osborne (1990) called a "respiraling effect' to enable a more complete illumination of the phenomenon" (p. 84).

The conversations with each participant were audiotaped and subsequently transcribed. I did much of the transcription myself as a way to review and immerse myself in what was shared. The tapes and transcriptions were used throughout the research process; I turned to them again and again—listening and seeking new insights into the experience and meaning of hope for each participant.

Journal Submissions

The second method of data collection was intended to supplement the conversations and provide additional ways to enter into conversations about hope. At the first meeting, each participant was given a journal. The women were told that the journal was theirs to keep and to use whenever (and however) they wished. As a supplement to our conversations, however, the women were invited to write about their experiences of hope – as close to the time of the experience as possible. To facilitate the writing, and as a reminder, I wrote the following in the front cover of each person's journal:

This is your hope journal . . .it is your journal to keep. It is your property, and your gift. If you choose to write about hope, here are some ideas for you to consider:

- *Write about your experiences of hope as you feel hope or soon after the experience.*
- *Write about hopeful incidences with people.*
- *Write down interactions or thoughts that were inspiring or hopeful.*
- *Things that were said, heard, or read through the course of a day that remind you of hope.*

If an experience of hope does occur, please describe it in as much detail as possible. Use these questions as a guide: What happened during the experience? Where did it take place? Who was there? What did you feel emotionally and physically? What were you aware of? What was it like?

The rationale for providing the participants with journals was based on the recognition of both the complexity of the topic of hope and the limitations posed by the length of time in between my conversations with the participants. The intention was to give the participants the *opportunity* to write. I did not want to impose on them, or to pressure them but to instead offer and provide a way for each to communicate in her own personal style, in a way that wasn't dependent upon my verbal prompting. Secondly, because this project took place over a number of months, the journals provided the opportunity for the women to record their experiences of hope closer to the actual time of that experience. Finally, however, it was my intention to provide a safe place for the women to go with their thoughts and feelings, should they arise. According to Sommer (1989), journals are a safe place to write without the restrictions of form, audience, and evaluation.

I suspected that not everyone would welcome the journals and that the women would each use her journal differently. Consequently I was not surprised by the participants' initial reactions to the journal. One woman was truly excited about the idea of writing in the journal, seeing it as a potential memento for her child. Another woman said outright, *"Don't expect too much from this!"*. Although not enthusiastic, the others nonetheless agreed to attempt journal entries.

The journals were distributed during the first formal conversation with each of the five participants. At each subsequent conversation, I asked whether there was anything the participant would like to share with me from her journal. One participant apologized each time, and expressed feelings of guilt, as if she had let me down by not writing in the journal! Another had used her journal for grocery lists, but kept hoping and intending to write more personally. Two of the participants used the journal regularly for personal entries, including entries about hope. One recorded her nightly dreams and wrote about her past as well as present feelings. The other began

to record her life story as well as her thoughts about hope. These two women read segments of their journals onto the tape, sharing what they had written about hope.

By buttressing the conversations and providing an alternative, individualized means for the participants to access, verbalize, and describe their experiences of hope, the journals served the purpose for which they were intended. Consequently, as a supplement to the conversations, the journals contributed significantly to my understanding of the meaning of hope for at least two of the participants.

Photography

A third form of data collection added an innovative and exciting dimension to this exploration of hope namely, the use of photography. Because it has been shown to facilitate conversation without the inhibitive effects of questionnaires, photo-assisted interviewing is an appropriate and accepted form of data collection in qualitative research (Collier & Collier, 1986). The use of photography has also been shown to allow for reflective interacting during interviews and assists in gathering selective and specific data (Gaskins & Forté, 1995; Harper, 1994). By asking each participant to take some photos of her experience of hope, my intention was to provide another way to describe and access the experiential.

The impetus for me to include photography came from photography exhibits available for display through the Hope Foundation of Alberta, entitled *Images of Hope*. *Images of Hope* is really two collections of framed photographs taken by amateur photographers. Each photo represents some dimension of hope captured by the photographer through the lens of the camera. The collections encompass images of sunsets, children, pets, and nature scenes. Additionally there are many though-provoking images – not 'obvious' depictions of hope, including a graveyard, a child facing (and dwarfed by) the smokestacks of industry, a tiny flower emerging from a block of concrete and a large weathered hand clasping the hand of a tiny infant. I have heard people respond to the *Images of Hope*—seeing in the images reflections of their experiences

of hope. Similarly, I have heard people say, "No, that is not my experience, I don't understand why that photo was included". Either way, in response to the photos, individual experiences of hope are confirmed and clarified.

During the second conversation, each participant was given a disposable camera, equipped to take both indoor and outdoor photographs. The participants were asked simply to take pictures depicting for them the experience of hope. The women were again assured that the photos would be theirs to keep. The intention was to "talk about" their photographs to facilitate continued and deepened conversation about hope. The women took the cameras and, after the photos were taken, I retrieved the cameras, had the photos developed and scheduled another conversation with each participant (conversation three). With the photos in front of us, I attempted to glean as much description about each photo as possible, using questions such as these to guide the conversations:

- Why was this particular shot taken?
- What was happening for you when you took this photo?
- What were you feeling?
- How does this picture depict for you the experience of hope?

Similar to the journals, the cameras yielded enlightening and interesting results, further contributing to the participant's descriptions of their experiences of hope. For example, I was not surprized to see photographs of children. However, the varying descriptions and comments from among the participants about *why* the children's photos were taken contributed an added dimension to the descriptions of hope, which I had not fully anticipated.

Images are evocative and offer an alternative form of expression than the spoken or written word. By placing the camera in the hands of the participants, *control* of the images and expression was placed in their hands as well. Because verbal description is a skill that varies from individual to individual, the use of photography was a helpful addition to the research process,

allowing for additional freedom of expression that hadn't been possible through conversation alone.

Reflecting (Contemplative Mirroring)

Aligning myself within the existential phenomenological traditions as outlined earlier in Chapter Three of this dissertation, I do not see myself as an objective voice removed from the investigation. Quite the contrary, my place in the investigation is acknowledged and integral, as all of the data are interpreted through the experience, insight and knowledge I bring to this exploration. Therefore, "who I am" (as pastor, theologian, AIDS advocate, feminist, etc.) cannot be separated from what is conveyed through these pages: I am the filter through which the women's experience is both conveyed and interpreted.

Integral to the investigating/reflecting process is the attempt to delineate themes from the data. In keeping with the general methodological framework of this phenomenological exploration, the sifting out of themes did not occur as a mechanistic breakdown of phrases or lines from the transcripts. Instead of thematic *reduction* of the material, thematic *reflection* took place in order to help concretize the experience, and bring into focus the meaning within and underlying the words presented. Thematic reflection as a way to bring oneself closer to the experience is "not a rule-bound process but a free act of 'seeing' meaning. . .a means to get at the notion we are addressing. . ." (van Manen, 1994, p. 79).

After each conversation with a participant, I recorded my thoughts and initial impressions in my own journal. Later, upon reviewing the transcripts, listening to the tapes, and comparing one conversation with another, I lifted phrases from the participant's own words or assigned words or concepts that seemed representative of what the participants meant. In some cases a word or phrase of the participant's captured just the right sentiment. At other times a theme was not obvious and I had to search out words from other sources that might convey a common theme. The delineation of themes came as a result of *contemplative mirroring*: the ongoing

process of reviewing the material, pondering and musing about what was shared by the women, and the sense, or underlying meaning of the words each woman used to describe her experience of hope.

Thematic analysis may be a useful tool for bringing one closer to the meaning of the experience, but thematic analysis always entails simplification, falling short of capturing the mystery of the phenomenon (van Manen, 1994, p. 88). Thus the hermeneutic process only begins with the delineation of themes. The *contemplative mirroring* process entails another kind of reflection: reflection upon the many ways the topic of hope has been expressed and illuminated. Consequently, it was important for me to become familiar with artistic, literary and poetic expressions and depictions of hope. While watching a film or video, I paid particular attention to expressions or feelings of hope. I explored art and poetry, seeking ways to illuminate the expressed descriptions of hope. Other phenomenological explorations were read (and re-read!) as I pondered the most effective ways to convey the meaning of hope through my own writing.

The intent of hermeneutic phenomenological writing is to portray the experiences of hope in a way that will resonate with others. Consequently, this type of investigation invites exploration of multiple resources that will serve to illustrate the descriptions 'drawing them out' in as evocative way as possible. Some of these resources have already been named; however, I created an additional method for gathering multiple resources, seeking input from friends and selected other individuals regarding my descriptions of the participants' experiences of hope. Because I was asking others to participate in the research, besides the participants, this additional method necessitated both an addendum to my research proposal and a return to the ethics review committee.

The addendum to the research included the following steps. First, I wrote a brief description of each of the participant's experience of hope which were handed out to various

individuals. This meant that each individual received five sheets of paper, five descriptions. Attached to each description was a question sheet asking for responses to the following:

- Is there a movie or scene from a movie, which for you depicts this person's hope?
- Describe a scene from a book (fiction or non-fiction) or a story, which depicts this individual's hope.
- Do you know of any poems that describe this person's hope?
- Is there a piece of commonly known music, which brings to mind this type of hope?

(An example of the handout can be found in Appendix D).

The descriptions and response sheets were distributed to a small group of people, primarily friends and acquaintances of mine. Calling these individuals 'literary wise ones', I asked them to return the sheets to me over a period of weeks. As the literary wise ones submitted their sheets, the range of responses were intriguing; a range of poetry and variety of films were named in relation to the descriptions. Most of the material gleaned from this source was not directly useful to this project, though the responses were extremely interesting. The most beneficial part of this segment of the research was the sparking of my own reflection in response to what was offered from the literary wise ones.

Prior to distributing the descriptive sheets, I contacted each participant and read the short description I had written. Verbal approval was given to me to use these descriptions in the way I had presented. This served the dual purpose of both securing permission for the use of the descriptions and providing a check for me from each participant regarding the 'executive summary' interpretation of her experience of hope.

There is a relentless seeking quality to this type of research that does not allow for simplicity or reduction. Indeed, the closer one gets to the phenomenon, the more one wants to explore it from yet another angle. Not unlike a diamond's multifaceted beauty, exploring the topic from many different angles can enliven phenomenological descriptions. Searching out literary allusions to hope, metaphors for hope, the words of poets and visual depictions in art or film was invaluable to me in gaining insight into the phenomenon of hope, to better understand the many

ways hope has been expressed. This dialogue with the literary and artistic sources provided a springboard for my own reflections, which were in turn interwoven in the text through the writing/reflection/rewriting process.

Describing The Phenomenon Through The Art Of Writing And Rewriting: Investigating/Reflecting/Writing

The six interrelated research activities described by van Manen take on life as they are brought to the written page by the researcher through the process of writing (and rewriting) the text. Although listed as one of the six activities (van Manen's number 4), the writing process is truly the thread tying together the entirety of the research endeavor. Indeed it is through the writing that one is able to reflect (van Manen's number 3), to maintain an orientation to the question (van Manen's number 5), to balance the parts to the whole (van Manen's number 6), and to bring subjective meanings to the level of intersubjective shared understandings (Angen, 1999).

In order to maintain a "strong, oriented relation to the question" and to facilitate "continual reflection on the essential themes" (van Manen, 1994), I kept a journal throughout this endeavor. The journal was used throughout the research process to explore the many interactions with hope that took place for me along the way, including: my reflections before and after each conversation; my responses and reflections of what I was learning through literature, art, film, novels, conversations, experiences and the responses from the 'literary wise ones'. The journal served an important purpose for me as the vehicle through which interpretation took shape, providing a way for my thoughts and feelings to come to the surface throughout the research process.

Here is an excerpt from my journal, written after a conversation with one of the participants:

> ***_____ has just described for me what it felt like to hear her physician say that her viral load was 'undetectable'. It was a wonderful description of the experience of hope and I felt her excitement as she described the experience. Even as I was listening to her relate the experience I realized how difficult it***

was going to be for me to convey HER experience. So much of the communication took place in the "space" of our conversation: her body language, her use of inflection, the pauses in the story, the gleam in her eye as she savoured the moment...What really struck me was the waiting time in the office—not knowing yet which way the test results would go...for her the good news, prompted her experience of hope...but during the waiting time, she must have wondered and braced herself for anything, good news or bad...I must remember to ask her about that next time...is that waiting time an important part of the experience of hope? Someone referred to hope as "the space in between"... in this case, not yet knowing the results. I wonder if, or in what way the waiting was a part of her experience? Or was hope experienced only in the moment she heard the good news...

(excerpt from Carol's journal)

Van Manen (1994) devotes an entire chapter to hermeneutic phenomenological writing which, for him, is the crux of the matter: "The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible" (van Manen, 1994, p. 125). Bringing one's thoughts to the page brings forth knowledge and insight, concretizing it for ourselves and others to see. Foucault (1988) claims that as we write we "test" ourselves, learning what we are able to say and how we say it. Writing then becomes a reflection of who the researcher is every bit as much as it becomes a reflection of the research process itself.

As part of the interpretive process I employed a somewhat innovative writing technique which I have included in Chapter Five under the heading(s) *A Snapshot of Hope*. Taking the liberty afforded within hermeneutic phenomenology, I have written these pieces by putting myself in the place of each of the participants. Using each woman's own words interwoven with my *impressions* of what she conveyed, I have written the *snapshots of hope* to bring myself closer to the experience as lived by the women.

With the exception of Chantal, the *snapshots of hope* describe actual photos taken and shown to me by that particular participant. However, the thoughts conveyed through the first-

person account utilize both actual words and poetic license. That is, the *snapshots of hope* are not lifted as entities from the transcripts. The *snapshots of hope* are included to give the reader the *sense* of each woman's experience. They supplement to the narrative descriptions, even as they summarize and bring to an experiential level that which has been conveyed conceptually.

Phenomenology depends upon the richness of the written description of the phenomenon. Hermeneutic phenomenology depends upon the interweaving of description and interpretation. It is interesting to note that in the revisions made to van Manen's methodological framework between 1990 and 1994 the writing step in the process was renamed "The *Art* of Writing and Rewriting"(van Manen, 1994, p. 30 emphasis mine). Hermeneutic phenomenological writing is not just about communicating information or conveying findings in a report:

> ...[phenomenological] writing is closely fused into the research activity and reflection itself...writing fixes thought on paper. It externalizes what in some sense is internal; it distances us from our immediate lived involvements with the things of our world... thus writing creates the reflective cognitive stance that generally characterizes the theoretic attitude in the social sciences. The object of human science research is essentially a linguistic project: to make some aspect of our lived world, of our lived experience, reflectively understandable and intelligible...(van Manen, 1994 p. 125).

If done adequately, the text should be evocative and thought-provoking, bringing the reader into dialogue with the topic and the interpretation of the experience. More akin to poetry than a technical report, the phenomenological text is to be written in a way that brings the reader closer to the experience of the phenomenon and enriches understanding about the phenomenon.

Trustworthiness

There is a lack of consensus regarding both terminology and procedures for establishing rigour across the broad range of qualitative research methodologies (Denzin & Lincoln, 1994; Sandelowski, 1993). A multiplicity of terms are used to describe rigour called for in qualitative

research. Reliability and validity (Morse and Field, 1995), trustworthiness and dependability (Cresswell, 1998; Lincoln and Guba, 1985), credibility (Eisner, 1991), and verification (Cresswell, 1998; Dukes, 1984) are just a few examples of the range of terms from which a qualitative researcher may choose.

Each term intersects and becomes reconceptualized as the true nature of the inquiry—description and interpretation—is kept to the fore. Valerie Janesick (1994) summarizes the problem: "Validity in qualitative research has to do with descriptions and explanation, and whether or not a given explanation fits a given description. In other words, is the explanation credible?" (Janesick, 1994, p. 216).

Unlike forms of quantitative inquiry, which demand strict adherence to procedures, hermeneutic phenomenology overtly acknowledges the reflexive nature of the process. Because it is interpretive, and therefore highly subjective, credibility is not measured pragmatically (e.g. did the researcher follow the proper *procedure?*). The final product becomes credible in relation to the following questions: does the description of the experience of hope resonate as true to others, (first, to the participants themselves and, next to the reader). Secondly, is the study believable; in other words, is it well-grounded and well-supported (Polkinghorne, 1989)? Thus, in an interpretive evaluation materials are evaluated by their ability to illuminate phenomena as lived experience. Such materials should be contextualized, relational, rooted in participant stories, include other forms of discourse (film, music, poetry), incorporate prior learnings about a phenomenon, and presented in ways that reveal the feelings and language of the participants (Denzin, 1994).

The phenomenological imperative of this study called for descriptions while the hermeneutic dimension called for interpretation. Phenomenological integrity was maintained through "member checks," deliberately seeking participant's reactions to my descriptions with the women progressed, I talked with each one about what I had heard described as her experience of

hope. Feedback was requested from each person regarding the accuracy of my description of her experience of hope and appropriateness of themes. If a song or poem seemed appropriate, I checked first with the participant before including it in the description. I talked with each one about my impressions from previous conversations and gave examples of how I arrived at a particular description. This took place individually and each participant was given the chance to respond to what I said (with the exception of one participant, with whom I had only one conversation).

Hermeneutic integrity was maintained by the constant reflection on the topic of hope, van Manen's (1994) fifth and sixth research activities: *maintaining a strong, oriented relation to the question and balancing the research context by considering parts and whole* (1994, p. 30). My concerns with trustworthiness prompted keeping these questions to the fore: will the end results of this research create a greater understanding of the experience of hope? Will the research illuminate the meaning of hope in a personally significant way?

Verification rests in the researcher's ability to clearly delineate procedures and decisions made, auditing the steps and influences along the way. A paper trail was kept throughout the research process, including a personal journal and detailed field notes documenting decisions, contacts, appointments and changes made throughout the research process (Lincoln & Guba, 1985; Morse, 1994). Conversations with the participants were audiotaped and transcribed. This kind of documentation helped to clarify the research process and given legitimacy to the study.

In spite of these assurances, by its very nature, a hermeneutic phenomenological inquiry can never be duplicated in a literal sense. The interplay between the interpretive dimension and the descriptive has made this study in a very real sense unique and time bound. This exploration does not portend to provide a universal definition, model or measurement of hope; it is contextualized to the particularities of the individuals involved and the interpretation of meaning *at this particular time.*

The concern then, in phenomenology is with "sameness of meaning" rather than applicability or generalizability. Gadamer's (1989) term a "fusion of horizons" comes closest to describing the intent. If through this inquiry I have been able to adequately convey the experience of hope so that it resonates as true to the participants and to the reader(s), then this exploration will withstand the standards of rigour and appropriate to hermeneutic phenomenological studies.

Ethical Considerations

Ethical approval to proceed with this project was given by the Faculty of Agriculture, Forestry and Home Economics Ethics Review Committee in November of 1998. Participants signed a consent form, the concept and content of which was first explained during the initial phone conversation (see Appendix C). The consent form was read out loud and discussed with each participant prior to starting the tape recorded session. The language of the consent form was direct and simple, and was read to the participant line by line to assure comprehension. To signify her agreement, each participant placed her initials after each item on the consent form. Each participant received a copy of the consent form which included my phone number as a contact. The consent form included a statement making clear two important items (1) that the participants may drop out of the study at any time without explanation and (2) that participation in the project would not affect the services offered by ASC in any way. The issues of confidentiality and anonymity were addressed initially and repeated throughout the project.

The very nature of the topic (i.e. hope) meant that this research would be both personal and evocative. From the start, I was well aware that the participants would be significantly involved. I knew that the conversations with me, interactions with their personal journals, reflections on my descriptions of their experiences, and their involvement with photography might elicit deep feelings and the expression of those feelings. In fact, I was wondered and had some concern about the extent to which this would take place. At the outset, I wondered whether the participants might share with me more deeply than otherwise intended, or whether their

expectations for what would come out of this project might exceed my intentions or the end result. I worried that the women might be disappointed with the final product. Moreover, I was concerned that their thoughts and experiences of hope might well be altered as a result of this project. As the women shared with me their stories, their hopes, their frustrations and their fears, I have been keenly aware of both the responsibility and the privilege of conveying their stories and their deeply personal experiences of hope.

CHAPTER FIVE

THE EXPERIENCES OF HOPE

Over the course of one year, on four different occasions I traveled to Bethlehem, Pennsylvania to engage in conversation with five women regarding their experiences of hope. In previous chapters I have provided the background to this study, situating it amidst the realm of hope research and in the context of HIV/AIDS in the United States. I have described the conceptual framework guiding my approach and the assumptions behind this project. In Chapter Four I have described the methodological guidelines undergirding this exploration of hope. In this chapter, I proceed with describing the experiences of hope as conveyed to me by the five participants.

In this chapter I will introduce each of the participants and describe each woman's experience of hope as conveyed to me during our conversations. I have revisited the tapes and the transcripts from the conversations many times during the past year as I have attempted to use each woman's own words as much as possible and remain true to her experience. I have included references to journal entries (my own and the participants') and descriptions of the photographs taken by the participants. Each woman's experience of hope is described through the use of themes, which emerged through the contemplative mirroring process.

This chapter thus presents the descriptive side of the descriptive-interpretive paradigm that is hermeneutic phenomenology. The title of the chapter, *The Experiences of Hope* highlights the individuality of each woman's experience of hope and conveys in part the multifaceted character of hope itself. The hermeneutic exploration of the commonalities within the women's experiences is presented in Chapter Six, which is entitled: *The Experience of Hope*. The two chapters read in tandem, then, portray the two "sides" of hermeneutic phenomenology (interpretive and descriptive) held in balance and creative tension with each other.

Chantal

"...I'm just too tired to hope..."

Chantal greeted me at the door on a bright and sunny winter day. As we walked up the stairs to her apartment, we moved towards and ultimately into complete darkness. The shades were drawn and no lamps were illuminated. It took some time for my eyes to adjust. Chantal held onto an infant and told me that her second child would be home in about an hour; he was attending a special day-program. Soft-spoken and petite, Chantal's frame and affect made her appear younger than her twenty years. Chantal was timid and nervous. She told me almost immediately that she was afraid that she would cry. Before she finished telling me this, she reached for a Kleenex as the first tears came: *"I don't talk about this much because it makes me too sad"*. In fact, as we settled in and she began to tell me her story, Chantal's voice trailed off frequently, muffled by her tears and the unspeakable pain. Parts of the recorded conversation, I discovered later, were nearly inaudible due to the softness of her voice.

Chantal had been living with HIV infection for just over four years. A series of blood tests were performed during her first pregnancy and Chantal was told then that she tested positive for HIV infection:

> *...[The Doctor] told me I was HIV positive and I was like, what? I'm <u>WHAT?</u> I had just eaten a hamburger and potato chips and as soon as he told me it all came up... I just started puking... my stomach was disgusted... I just couldn't calm down and I was there all by myself and I was like, what? What are you talkin about?... And then I said, that can't be true and I started to leave, and I said to myself 'calm down, calm down'... There I was, four months pregnant. The nurse said, 'what are you going to do about your baby?' And I said, 'I don't know what I'm gonna do' it felt like they were picking on me, putting pressure on me. I never thought about AIDS and I only had unprotected sex with one person... so I was like, 'This isn't true! He told me he took really good care of himself... where is this coming from?'... I was so upset, they admitted me right then and... and put me on a suicide alert...*

During her hospitalization Chantal was immobilized and unable to eat: *"...I'd just sit there for days at a time... I couldn't move, I couldn't talk... I was so depressed"*.

Upon hearing of her diagnosis, Chantal was in shock. She explained the time with such emotion that it was evident this marked a tragic turning point in Chantal's life. I soon learned however, that this was but one among a series of hardships in Chantal's life, Nevertheless, it was HIV which permeated Chantal's thoughts and initiated the flow of tears during the first moments of our conversation.

Chantal continued, sharing her story in a subdued tone. The father of her child was both Chantal's first sexual experience and the one from whom she became infected with HIV. Chantal had not wanted to become pregnant but the boyfriend often refused to wear a condom during sex. After she became pregnant, the boyfriend insisted that she should get an abortion, but Chantal said she wouldn't do that, *"I just couldn't have an abortion; I couldn't even think about it"*. Chantal shared with me her belief that the boyfriend must have suspected (or knew) that he was HIV positive while they were sexually active, because of his insistence about the abortion.

Early in their relationship Chantal's boyfriend became physically and emotionally abusive towards her. After their son was born, the cycle of abuse continued and increased; Chantal became more fearful, first for herself and later for her child. After nearly four years of abuse and facing another pregnancy, Chantal took her child and fled the relationship. The ex-boyfriend did not accept the move lightly, repeatedly tracking down Chantal. Chantal lived in fear of her 'ex'. Consequently, she changed her phone number and living arrangements frequently.

Chantal's first child was born in 1995 and did not develop HIV himself. He was however, born with severe special needs, unrelated to HIV. Her second child, a daughter, was less than a year old when I met Chantal. Because they share their mother's immune system, all infants born to HIV positive women are born with the virus. It can take up to eighteen months until it is known for certain whether the child will remain HIV positive. When I met Chantal, her baby was taking preventative drugs:

> *...After my first one... I really didn't... I don't say I didn't want her, but I just didn't want to put another child through it... it is a lot of stress taking the medication... and it's difficult... they had her at the hospital once a week; she was on AZT now she's on Bactrim... she's is good... so far... She did just have a cold, which of course scared me... but they really won't know until she is a year or eighteen months...*

Chantal told me that she didn't want to give up, *"because of her children,"* and yet she found it difficult to "deal with" the HIV. Through tears she said, *"if I think about it, it stresses me out. ... I've had it for four years, and you'd think after four years that I could deal with it, but I can't"*. Because of the daily requirements of her son's special needs, the demands of her infant and her own illness associated with HIV infection, Chantal was unable to work.

Her involvement in an abusive relationship, the birth of her special-needs child and infection with HIV coalesced during a short time span in Chantal's life. Prior to meeting her boyfriend, Chantal had planned on becoming a nurse, and becoming financially stable. She had always wanted children, her own home, and a partner with whom to share her life. She told me that she had once been independent, intelligent, and happy-go-lucky. When I met Chantal that day in the darkness there was no sign of a happy-go-lucky girl. She appeared instead as one in shock – paralyzed and utterly overwhelmed by the path her life had taken.

Except for occasionally seeking help from the local AIDS Service Organization, Chantal shouldered her troubles in isolation. Because she had heard both her mother and her sister say prejudicial things about people with AIDS, and witnessed her family reject a cousin with AIDS, Chantal was fearful of disclosing her HIV status to anyone in her family. She was disappointed in her sister, who as a nurse, Chantal claimed "should know better" than to feel or voice disgust towards persons with HIV/AIDS. In particular, though, she deeply felt the loss of connection with her mother. She was sobbing as she said to me, *"I mean, I'm her <u>daughter</u>. Who am I supposed to turn to, if I can't turn to her... a <u>stranger</u>? Sometimes I just want my mother"*.

There was a certain degree of awkwardness in the conversation with Chantal. I arrived anxious to attend to the task at hand, to talk about Chantal's experiences of hope. I tried many

different ways to broach the subject, but Chantal needed instead to talk about the frustrations of her life. As she did the heaviness of her story and the surrounding darkness enveloped both of us. I began to feel the downward spiral in which she was caught. Feeling some guilt in trying to steer the conversation in a direction Chantal was unable to go (talking about hope), we talked instead about the hopelessness and what that was like. Chantal was definitive that she experienced her current situation as "hopeless".

At one point I asked whether Chantal could remember a time of hope since HIV. She answered with the following:

> *... Carrying her... [daughter], being pregnant... When I was pregnant with her I was so depressed again. I was suicidal, and just sat by myself for three days at a time... I was so upset... but then I said, OK, you have to do this for your baby. So I ate... and I try now to give her medications so that she stays healthy, so that she doesn't have to go through what I am going through..*

When I attempted to find out more about what that experience of hope was like for her, Chantal's response was to hang her head and say softly. *"I'm just so tired I can't even think about hope".*

Awkwardly, I explained the process for using the journal and the camera. Just after I explained to Chantal the use of the camera and journal, her son's bus arrived and our conversation was cut off suddenly and there was no returning to the subject. I immediately understood what a handful the child was.

I never saw Chantal after that day. On two consecutive trips to Pennsylvania I tried unsuccessfully to again contact her. Her case manager finally told me that Chantal had left town abruptly leaving no forwarding address or way to contact her. Because there was no contact with her after that first conversation, I have no way of knowing whether she ever took any pictures or wrote in the journal I left for her. As I was leaving, she put the mail pouch with the camera high on a shelf safely out of the reach of her four-year old. As she placed the camera on the shelf it

crossed my mind that Chantal might not ever use it. I've often wondered whether Chantal packed the camera with her other items as she left town, or whether she discarded it in her hurry to leave.

Chantal's Experience of Hope

Chantal knew I was coming to talk to her about hope. She agreed to participate in the study at the urging of her casemanager and another participant, knowing the study was about hope. Despite my best efforts, very little about hope was discussed. Chantal told me that she thought she was hopeful before becoming involved in the abusive relationship, but she really couldn't remember what it felt like. Talking about hope, even thinking about hope was an effort, 'one more thing' for Chantal to deal with. She was "too tired" to hope. Chantal could not talk about hope, think about hope or access the experience of hope. Does that mean she was without hope? I have asked myself these questions repeatedly since that first and only conversation with Chantal.

Waiting in the Darkness

> *When I cry, I close my eyes and every tear falls down inside and I pray with all my might that I will find my heart in someone's arms when I cry, cry when I cry, when I am sad I think of every awful thing I ever did. When I cry, cry, cry The salt inside my body ruins everyone I come close to my hand are barely holding up my head Oh I'm so tired of looking at my feet and all the secrets that keep my heart is barely hangin by a thread hangin by a thread oh look at me at all I've done I've lost so many things that I so dearly love I lost my soul I lost my pride Oh I lost any hope of having a good life so I cry, cry, cry the salt inside my body ruins everyone I come close to my hands are barely holding up my head oh I'm so tired of looking at my feet and all the secrets that I keep My heart is hangin by a thread by a thread I miss you all I wish I was with you now I wish I was...*
>
> *("Hangin By A Thread", Jann Arden 1997)*

Chantal appears to be "hanging by a thread". She hangs on but one gets the sense that her grasp is weak and the 'thread' fragile, barely able to carry the weight at its' end. Like the person in the song, whose eyes were closed, Chantal too sat in the darkness of hopelessness. It was clear to me both from her words and from my feelings during the conversation that Chantal was

currently in a time of hopelessness. Nonetheless, she had not committed suicide and had made changes in her life, which signaled some desire for survival. What is that thread to which Chantal clings? Might that thread itself be hope?

Two of Chantal's comments related to hope provided me with some insight into her experience. First, Chantal talked about her children, wanting to stay healthy "for them" and to make their lives different from what hers had been. She also mentioned a social worker who had been assigned to Chantal during her first hospitalization. The social worker befriended Chantal and did not give up on her. She was unwavering in her visits. While Chantal was in the midst of her deep depression this woman often just sat with Chantal in silence during those dark times. Consequently, the social worker became one whom Chantal could later talk with and depend upon. Chantal told me that the social worker had continued to keep in contact with her, but recently Chantal had not been returning her phone calls.

Chantal's downtrodden affect, her subdued demeanor, the tragic dimensions of her story, and the heavy darkness of her apartment all contributed to my sense of Chantal's hopelessness. Chantal's words *"I am too tired to think about hope"* have stayed with me and many questions about Chantal remain unanswered. Mainly I have wondered whether she still lives in such darkness.

In this study, Chantal is presented as an example of the experience of hopelessness. Still, she must have hoped for something – otherwise why would she have agreed to participate in this study? Why would she have "opened the door" and let me enter her space in such a way? Is there a hopefulness in allowing others to reach out to us, from within the darkness? Roots and new growth are initiated in darkness. But a sprout shielded from the sun's rays will never grow. Chantal draws the shades, locks the door and screens her phone calls, living in fear of her former lover. Do these barriers also protect Chantal from the possibility of hope entering her space? Or does Chantal's darkness provide a safe place, a waiting space from which hope may emerge?

Chantal: A Snapshot of Hope?

I just don't know what to think. Carol is nice, just like Grace said, but I don't know if it's worth trying to talk about hope. She wants me to talk to her, but every time I think about AIDS I just get sick to my stomach. So much has happened to me. My life hasn't turned out the way I planned. Once I got involved with my boyfriend my life just went downhill. I got pregnant and then the HIV and then the beatings and now I am just so tired... I told myself I wasn't going to cry but here I am with the tears just flowing down. I don't know if I have any tissues in the house, I haven't gone shopping in so long.

My social worker called the other day but I just didn't feel like talkin' to anyone – even her – and she calls me all the time. Here is another question about hope... Carol keeps asking me and I don't know what to say. I don't know why I can't talk about it: all I can think about is how hard everything is—it's like the whole system is against me. I can't get a job; I can't get child support; I can't get away from my ex. I feel so alone and I just want to be left alone. And now here I am thinkin' and talkin' about my mother. Why can't I just tell her about the HIV? I really need her, but, I saw her reject my cousin, not letting him in her house anymore because of his AIDS. So what am I supposed to do? I couldn't bear it if she rejected me, but I can't tell her. I just feel all alone. Now my stomach is getting upset.

Carol is getting ready to leave and she's telling me about the camera. She wants me to take pictures when I feel hope. I'm not sure I understand but she's giving it to me anyway, says she wrote it all down for me... a camera... what am I supposed to do with that? I have to keep it out of the way so that my son doesn't get a hold of it. I'll put the package up here on the shelf in the corner where he won't see it. I can barely reach up there so he for sure won't get to it... the bus'll be droppin him off soon, I don't have much food in the house and he'll be hungry...

I feel bad that I cried in front of Carol and that I couldn't talk about hope. I just need some things to change and I can't seem to get anywhere. Carol says she'll phone next month; I can't even think that far ahead; I may not even be here... who knows what'll happen by then... I'm just so tired, too tired to hope I guess...

A Representation of Chantal's Experience of Hope

Figure A depicts Chantal's experience of hope. She stands alone in relation to hope, having no connection to the word. Hope is accessible to the figure, but it is unclear what may potentially initiate a connection or spark hope. She is waiting for hope.

HOPE

Figure A: A Representation of Chantal's Experience of Hope

Christa

"I think of hope as a beam of sunlight on the snow hanging on the trees outside my window... "

Proud of her German roots, Christa's voice mail greets callers with *Wie Gehtes!* At the time of this research Christa was forty years old, living with her only child, a six year old son. Having lived many places (including Germany for a time), Christa finally settled in a small town in Pennsylvania, near the place of her childhood. Christa became a client of the AIDS Services Center in 1995, when her son was still an infant.

Christa was diagnosed HIV positive sometime in 1992, but told me that in all likelihood she was infected sometime prior to 1989. One of Christa's partners, with whom she shared both needles and sex, had died from AIDS in 1989. At the time of her partner's death, Christa was heavily addicted to drugs and alcohol. Her addictions shielded her both from the pain of his loss and from taking care of herself. Christa referred to her years in Germany as *"the really bad time in her life"*, times that included drugs, alcohol, sex, and prostitution.

When she became pregnant Christa abruptly ended a life of prostitution and "drugging". Consequently, Christa claimed her son to be the source of her hope. In her words, *"He is my hope, in fact, he's the reason I'm alive today"*.

A definitive "no nonsense" kind of gal, Christa described herself as a "fighter" who has left her past behind. She said at one point, *"I just don't let myself think about the bad stuff"* . For Christa this meant her own past, getting sick, or dying: *"If I think too much, I just get depressed, so I don't think about it; I just keep trying to have a positive outlook"*.

Christa was very proud of the fact that she was enrolled as a "mature student" at a local community college. Earning her Bachelor's degree was just one of a list of goals Christa had set

for herself: *"I believe anything is possible; you just have to put your mind to it!"* Proudly reading an excerpt from her hope journal, Christa declared these goals:

> *... By January 1, 2004, I will have in my possession a college degree and I will be on my way to entering a well-paying job that I will be happy with. My ultimate goal is to be the owner (or president) of a well-known business. I will be living on a small farm with my son, lots of animals, my friends and a significant other. I will have a limitless supply of the universe's riches. My son and I will live to a ripe old age and do lots of travelling...*

I arrived at Christa's apartment and she greeted me with a big smile and a hug. I knew Christa, through her involvement in the support group years ago. She was glad to see me, but she appeared nervous. It had been four years since I had last seen her. I noticed immediately the changes in her stature—the weight she had lost, the dark eyes, and sunken cheeks. Noting my concern, she assured me that she was doing well, *"I just have this wasting syndrome that's all, but I'm doin' good... Especially compared to other people!"* I asked about her son and was told that he was playing with a friend; Christa wanted no interruptions. I soon realized that Christa was actually eager to participate in this study.

Christa's apartment was small and bright with more windows than wall space. I noticed trees outside the window, and commented on how lucky she was to have such a view of the woods. *"What do you mean lucky?"* she replied, *"That's why I chose this place!"* There was little time for small talk as Christa directed me toward the dining area. A halfhearted offer of lemonade was made as she sat down directly across from me, folded her hands in front of her on the table. "*So, Carol"* she said teasingly while I plugged in the tape recorder, *"you're going to tell the world about us, right? Are you going to make us famous?"*

Christa rushed me through the informed consent questions, sometimes cutting me off before I finished the sentence, *"Yes I understand Carol". "Yes Carol."* She was eager to get down to business and this other 'stuff' was mere formality. "*Hey Carol, When this is all finished, do I get a copy of it?"* We were almost finished with the questions of consent when Christa paused, contemplating that to which she had just agreed. Referring to the confidentiality and

anonymity questions, she said definitively, *"Wait a minute! I don't mind you using my own name! I'm not ashamed! Hey, I want everyone to know about us [women with HIV]. Go ahead and use my real name."* We discussed this awhile, talking about the potential ramifications for the other participants, herself and/or her son. *"Yeah, OK, now I get it. That does make sense."* Just that quickly Christa got excited about choosing a name for herself: *"Call me 'Faith'... cause I have faith I'll be here another forty years!"* She giggled and I thought she was joking so I offered the name I had been contemplating for her. Crinkling her nose and shaking her head she dismissed my suggestion saying, *"I don't like that one, it'd take me too long to get used to it."* With these two names hanging in the air, it wasn't long before Christa asserted her final decision. *"O.K., I've got it. I'll be 'Christa'... that's 'Christ' with an 'A'. There, that's that! Now roll the tape Carol. Let's go; I'm ready."*

Christa's Experience of Hope

When asked to tell me about an experience of hope, Christa responded with a question of her own: *"Does it have to... should it be like, something good?"* My response was for her to simply share what first came to mind as an *experience* of hope, without worrying about "good" or "bad". Christa then told of the following experience:

> *...I guess when I was pregnant. It was an experience of hope because when I first found out, I tried every which way to get an abortion, because I was scared and everybody was telling me this and that [about AIDS]. But I was too far along in the pregnancy. I tried for almost a week. I went to one place and they wouldn't do it because I was sixteen weeks along. Then another place wouldn't take my insurance...*
>
> *So then I decided to go to New York even though I would've had to stay overnight because it was a two-day procedure. But then I found out it would cost seven hundred dollars! And on top of that, I had trouble getting a ride to New York. So I just sat down right then, and said to myself, 'you know what? Somebody wants me to have this kid, so I'm gonna have it!' That was hope to me!*
>
> *And then I made a pact with God, I said, 'If you let this kid be alright I'll stop drinking and doing drugs.' From then on, I felt pretty good! So,when I was pregnant, that was pretty good... that was hope...*

New Beginnings

Why did Christa wonder whether hope had to be something good? The experience she related was "good" in the sense that the outcome was positive: she changed her lifestyle and birthed a healthy baby. The recollection of the birth of her son was the experience of hope that first came to her mind in response to my question. Thus, from her perspective this experience was a time of hope. Because she equated the word hope with something "good," she wondered about the appropriateness of discussing the context of addiction and prostitution within which her child was born. Being neither proud of nor eager to recount the details, Christa did not want to spend much time talking about those years. Still, they were a critical to her experience. Like a phoenix rising from the ashes, Christa emerged from her own hopelessness ready to begin anew. Leaving her past life abruptly, Christa began a new life, sober, drug free, and bearing a healthy child, who was her hope.

Christa's life was marked by times of new beginnings, some of which had been major, some less dramatic. She had moved her belongings often in her forty years of life, settling and beginning again in various new living arrangements and geographical areas. She had worked new jobs, started new relationships, and even changed countries, starting over many times. At the beginning of this research, Christa was embarking on another 'new beginning', returning for a college degree. She was looking forward to finishing her degree primarily so that she could begin again at a new job.

New beginnings were important to Christa even on a day-to-day level. She tried to see each day as an opportunity – offering the chance to learn something new, to become a better person, and to stay sober and healthy: *"... I don't know, I just try to see each day as a new beginning, a chance, you know for renewal."* This dynamic was epitomised for Christa in the dramatic turnaround associated with the birth of her son, the time she associated with hope. The

birth of her son both defined and coloured her life, becoming for Christa the quintessential experience of hope.

Christa talked about her life using contrasts: *"Before [child] was born I was like hopeless, like, whatever... I didn't care about nothin'... "* A life of addiction and tough living marked the time 'before' when Christa had no goals, no ambition, no vision for the future. The primary characteristic of the time before was a lack of concern or care for anyone or anything. Contrasting with 'before' was the 'now' of Christa's life. *Now* Christa cared about her son and about her own well being, she cared about a certain quality of life, and she cared about how she lived her life: *"... Now I've got plans... and I've got my son to worry about."* In contrast to 'before' 'Now' Christa had goals, ambition, and dreams for the future.

For Christa, hope appeared to be experienced in the process of caring about someone, in response to her feelings for her child. I found myself wondering whether hope prompted Christa's renewal or whether hope was experienced in the process of renewal? Was hope that which allowed Christa to envision a future? Or hope that prompted a new beginning?

In one and the same thought Christa attributed her new beginning to HIV and her child's birth: *"If I wouldn't have gotten pregnant, I would still be like that [hopeless, addicted to cocaine and prostituting herself] ... but I am becoming a better person"*. She remembered the years she spent in Germany as hopeless times, but she did not want to dwell on that part of her life, saying, *"... that's just, life in the past."* The past was behind her and therefore unimportant. The important thing was renewal, the fact that she *was becoming*, in her words. *"a better person"*.

Rearranging One's Thinking

> *...I don't like to hope 'cause I like to think positive. . .just forget the hope and think this is going to happen. It's like this Carol, I don't hope I'll live to see my child graduate from college, I know I'm going to see him graduate! That's the way I've rearranged my thinking. . .and here's another one: I don't think I'm going to graduate, I know I will".*

Christa made a distinction between concepts such as hope, faith, and thinking positive. In this quote hope was described as a less powerful force than what was possible from her cognitive

capabilities (thinking positive), as if hope would not empower her to attain her goals. On the other hand, if she "thinks positively" about her goal, action will necessarily follow; she will have the motivation to move toward and attain her goal(s). Similarly, hope was not as strong a force as 'knowing'. In Christa's schema thinking initiated action, which was as equally powerful as 'having faith' that something will occur. At another point Christa's stated: *"...I hope to see my son graduate and I have faith that I will"*. On another occasion Christa read an excerpt from her journal, which included the words hope, faith, and wishing; and it was evident that for Christa each word had a specific meaning:

> *...Hope, to me means wishing for something so hard that it becomes a reality. Hard work and faith go along with that. I know and I hope I am here to see [child] graduate from college. Ihave faith that with good guidance and lots of hard work he'll make it and I know God plans to let me be around...*

As I looked around Christa's apartment I noted that it was a home put together thoughtfully. Cozy and neat, the rooms were dotted with pictures on the walls, plants, toys, books and lots of various small items. Though the apartment was full, everything had its place. Moreover, I got the impression that the things were placed in a certain way, with intentionally. Later Christa confirmed my first impressions as she showed me around the apartment.

Christa explained in detail the placement of the furniture, the pictures, and the smaller items. The sofa was placed on a certain wall because *"that's where the sun comes in"*. A plant was placed "just so" next to the birdcage *"so that the bird would be happier"*. Angels were hung over the bed in her bedroom to *"keep watch over me"*. The windowsill provided the opportunity for an altar of carefully arranged items which held meaning for Christa. There was a seashell placed next to a ceramic 'lucky pig'. A crystal given to her by a friend sat next to an equally meaningful trinket given to her by the same friend. A small, framed photograph of her son was lovingly placed amidst the items. Christa arranged her apartment, and the special items, with purpose. They were reminders, placed in a way that both lifted her spirits and provided inspiration.

As I looked around Christa's apartment, I remembered an expression Christa used. The phrase provided a link between what I saw in her apartment and the way she had told me that she *"rearranged her thinking"*. Did Christa 'place' items in her mind in the same way in which she placed items in her home? Did she rearrange her thoughts to include hope, by re-placing hopelessness with positive energy and positive thoughts? Once sensing her cup as 'half-empty,' did she rearrange her perspective to see it as half-full?

Often those with HIV experience the time of diagnosis as a time of hopelessness. Christa was already experiencing hopelessness at the time of her diagnosis. She 'rearranged her thinking' in order to view her diagnosis in a positive light: *"... HIV is a gift from God; it made me change my way of life... Well, actually my child did... but he probably wouldn't have come along without all the other stuff going on... so... "*

Christa was HIV infected before becoming pregnant and she was using drugs and involved in street life. HIV, addiction and prostitution were interrelated facets of Christa's life before her child was born. Her pregnancy occurred in the middle—and as a result of—her lifestyle. Because the pregnancy and birth of her child ultimately engender change and are "good", Christa rearranged her thinking to incorporate the range of realities, seeing everything as part of a larger picture. Consequently she saw HIV as a "gift from God".

<u>Child is Hope, Hope is Child</u>

Christa's relationship with her child incorporated all of the sentiments one usually associates with mothering: protective love, incentive to build a good or better life for her child and a deep desire to care for him and his well-being. There was something in Christa's relationship with her child however, that was unique. For even though other participants spoke similarly of their children, Christa was the only participant who said unequivocally of her child, *"He is my hope"*. What does Christa mean when she says that her child is her hope? Does she

mean that hope is tangible in the same way a child is tangible: physically present and real to the touch?

In the provocative film Life is Beautiful (Benigni, 1998) set in the early 1940's, an Italian Jewish man and his son are forcibly taken from their home and imprisoned in a Nazi concentration camp. In order to protect his son from the reality of the atrocities around them, the father creates a fantasy world for the two of them. The father tells the child that the angry uniformed guards barking out orders in German are really just part of a widespread game which includes the whole "camp" the other men in the barracks, the father and the son. The uniformed men are just pretending to be nasty, says the father to the son. Upon their arrival to the camp, one guard begins to shout at the prisoners in German, obviously giving instructions designed to keep the prisoners in line. Since the child only understands Italian, the father "translates" the guard's words for his son, telling the little boy that the guard is explaining the rules of the game. The object of the game is to win points, which are tallied at the end of each day. Staying hidden, not showing fear and not crying for ones Mommy win points. And, there will be no asking for lollipops! At the end of the game the team with the most points wins a huge prize: a real tank!

In Life is Beautiful, the father sacrifices *for* his son. Exhausted at the end of a brutal day's work, the father musters up energy to continue the façade for his son who has stayed hidden alone in the barracks all day long. Animated, the father proudly displays and gives to the son his own morsel of stale bread, claiming it to be a treat – a token of 'how well' their team has done that day! "We are winning", says the father! "See how many points we have earned today!" Even as he is being marched away at gunpoint seeing his boy for the last time, the father keeps up the charade. Everything is done for the sake of the child. The father has placed his own fears and feelings to the side in order to insulate his young boy from the horrors of humanity.

There is a contrast between the relationship of father and son in Life is Beautiful and Christa's relationship with her son. In the film, at all costs the father shields the child, *making* life

'beautiful' for him, even when life is truly ugly. For Christa, life is beautiful *because of* her son. He has given Christa a reason to live, to begin again and to care. Her child is Christa's hope. Unlike the father in the movie, hers is not a selfless giving. Instead, she received a gift form the child. She experienced care *because of* the child. Without her child Christa would have neither feelings of care nor an interest in goals. Without her child Christa would still be in a place of hopelessness. Without her child, her addictions may have ended her life. *Because of* her child, Christa was able to have dreams, plans, goals; she was able to manage her finances and remain drug and alcohol free, no longer tied to life on the street. She was able to begin again and make drastic changes, rearranging her thinking and her life *because* of her child:

> *... So I just sat down right then, and said to myself, 'you know what? Somebody wants me to have this kid, so I'm gonna have it... And then I made a pact with God, I said, 'If you let this kid be alright I'll stop drinking and doing drugs.' From then on, I felt pretty good... that was hope...*

Christa's Photos

Christa enjoyed both the photography and the journal dimensions of this project. She wrote in the journal regularly, utilizing it in her own way:

> *... I don't know, I think... sometimes I write in the journal, like, I guess, just to get it out... Like, if something pisses me off, I write so that I don't dwell on it... sorry, Carol, I know this not what you have planned... maybe you should rename the project 'The Life of an HIV Positive Person'...*

Nearly all of Christa's photographs included her son: in the bathtub; in a superman outfit; playing outside in the snow; playing in his room with his toys; all dressed up ready to go off to church. Interestingly, Christa didn't have much to say about the photos; it was as if they spoke for themselves. She had also asked a friend to take some photos of the two of them together – Christa and her son. One of the pictures showed the young boy on Christa's back, and their two faces looking at the camera and smiling. They were at a playground and thus trees and colour comprised the background. Photographically, it was the best among the bunch. When Christa saw

it she was disappointed because of the circles under her eyes and sunken cheeks. That picture prompted this response:

> *...just look, you can really see it [HIV/AIDS] in my face. When I started this new medicine, I got my blood test back and it's kind of pissing me off, but my Doctor keeps saying 'it's okay, it's okay.' Like my overall percentage of cells is like 39% but my T-cells have dropped again, right down to 340. But my Doctor's always saying 'don't worry about the T-cells, worry about the overall percentage'. But, you know, my viral load has been undetectable so that's good. The only think I've got is this wasting, or whatever... so, I don't know, I'm doing good compared to some other people that are in and out of the hospital...*

A Snapshot of Hope: Christa

My son just went outside to play; so I think I'll try and get some studying done while it's quiet in here. I feel pretty good today even though I'm still losing weight and my skin's all broke out from that one drug I'm on. If I didn't have this wasting syndrome everything would be perfect. But, compared to lots of other people, I'm doing good. Yesterday I took a walk with my friend Nancy through the woods and up to the quarry. We collected a bunch of pretty rocks and some fossils while we talked, but we really went looking for crystals. She's been giving me lots of books to read, some kind of, I don't know what you call em... spiritual books I guess... to keep me thinking positive. And so we were talking about some of the stuff I've been reading in those books.

We found some crystals while we were at the quarry and Nancy picked a really pretty one for me. I've got it there on the windowsill with my other treasures: my "lucky pig", my Christmas angel (which I keep there all year long), and a picture of my son and some seashells. The crystal will remind me of Nancy and all the good talks we've had. She says that crystals help with healing and so I'm supposed to look at it a lot or hold it in my hand so that I will get healing energy.

I haven't written in it much, but today I wrote in the journal Carol gave to me and this is what I wrote: 'Hope encompasses all your dreams, and dreams are what makes a person live! I have great dreams, and even greater hope! I believe... I live... I love... I am!!'

I am going to see my Dr. today. So maybe I'll take that camera along that Carol gave to me and take some pictures of my son. It's a nice day and, after all, without him I wouldn't have changed my life, I wouldn't be where I am today. Well, I'd better just take a look out the window and see what he's doing. There he is on that swing somebody hung on that tree. He loves to play in the snow... he looks so happy... and he's so handsome... I think of him as my little angel.

It is so pretty out there right now. I love to see the sun shining on the snow like this and with those few flurries floating around just glistening in the sun... It's pure, and peaceful... reminds me of something new, like, a renewal or somethin like that... I'm gonna get that camera right now and take a picture right out this window! This is good... I feel good... I can't wait to see my Dr. and see those blood test results. I just know they're going to be great!"

A Representation of Christa's Hope

Figure B, depicts Christa's experience of hope. The figure encompasses not one but two individuals. The larger of the two represents Christa while the smaller represents Christa's son. For Christa, hope *is* her child. Once carried within Christa's body through pregnancy now he is

physically separate from her: he is embodied hope. The image of the sun connotes the intimacy of the connection between the two figures, and the interconnection of Christa's hope with her son.

Figure B: A Representation of Christa's Experience of Hope

Anna

"...Looking at my pictures with the mountains and the blue sky and the clouds and the sun shining on the snow, all I can say is, that's what I'm hoping life is going to be like when I leave this world... I'm hoping it's going to be as beautiful as my pictures are and as peaceful as those pictures are..."

Anna turned forty-one years old during the course of this project. Anna grew up in a close-knit family, the only girl amidst three brothers. She worked most of her life near her family as both a server and a bartender in local establishments. Married at a young age, Anna's marriage ended in divorce, with no children. After her divorce, Anna began dating and, over the next few years, became involved in a few casual and longer-term sexual relationships. During those years Anna vaguely knew about HIV, but believed it only to affect certain 'types' of people (gay men and prostitutes).

Negotiating safer sex was not part of her experience before, during, or after her marriage. Anna simply never thought or worried about HIV; and her sexual partners never mentioned the topic. Anna became HIV infected sometime after the dissolution of her marriage, during that

period of casual dating. Anna first learned she was HIV positive five years prior to her participation in this research, when she attempted to donate blood. Upon receiving the news that her blood had tested HIV positive, Anna was completely stunned, as she had no idea that "someone like her" could become infected with HIV. Anna remembered with clarity the moment she was told she tested positive for HIV:

> *...I was hysterical... totally freaked... scared... and angry... I didn't know the difference between HIV and AIDS... I felt as though I was going to die right then and there... I had no idea someone like me could get infected... it was later that I started hating myself and I felt, well, dirty... and cheap... but just at that moment when I heard those results I was hysterical... that's the only word for it... "*

There in the office of the blood bank, with her friend present to hear the news, Anna realized that her life would never be the same. Bewildered and devastated by the news, Anna shared the test results with only a few close friends and family members. Living in a rural resort area where *"everyone knows everyone else,"* Anna feared rejection by others, worrying about her job and the way others would respond:

> *...I know what would happen. Like, I live right across from the ambulance garage. I mean, if I hurt myself and they knew I was [HIV] positive, they'd never come to help me! They'd just take their good old time... That's just the way it is... I know these guys!*

Anna first told her family that she was HIV positive. Although knowing little about HIV/AIDS, they responded with love and support. Anna's brothers were certain that Anna only had a short time to live and so they set out to fulfil Anna's life-dreams. They purchased a parachute jump for Anna and provided her with a hot-air balloon ride. Anna's father was determined to find a cure for AIDS and so he searched the news for the latest HIV treatments and drug experiments. He was particularly intrigued by the (then) current interest in bone marrow transplants from monkeys to people with AIDS.

Anna's mother accompanied Anna to her many appointments and tried to keep life in the household as normal as possible. The friend who was with Anna when she received her test results remained a faithful companion who consistently made herself available whenever Anna

needed her. Anna had this to say about her friend: *"She was the best friend I had, I could call her on the phone any time of the day or night; she was always there for me."*

Anna's co-workers and management did not demonstrate the same support and sensitivity as that given by her family upon hearing of her HIV infection. After disclosing her HIV status, many whom Anna considered to be friends rejected her; and she was forced out of one job as a consequence of disclosure. There was anger in her voice as Anna talked about these experiences of HIV-related prejudice:

> *... [having HIV] you learn who your true friends really are... who you can trust, who you can't trust..who sticks by your side and who doesn't...*
>
> *...I told my boss about my having HIV, I thought he was a friend, but deep down inside it ended up that he wasn't a friend. One day I went to work and saw these tablets that go in the dishwasher. It says right on the bottle 'prevents HIV'. We never used those before, not in ten years! But all of a sudden, after I come up positive, then the pills came out to put in the water to sanitize it...so I knew that was the time to make a leave real quick. He said things like, "[he was] afraid that no one would come to the restaurant if they found out I was working there and HIV positive"...so I ended up giving up my job because the pressure was too much; you know...*

From the beginning, Anna experienced general physical malaise and severe side-effects from HIV medication. This coincided with a series of emotional setbacks as well. Just a few months after her diagnosis, Anna's father died from a sudden heart attack. The entire family was shaken as the father had been the center and the backbone of the family. More personally, Anna told me that her father had been, *"..[her] "rock, strength, and support... I was always, you know, Daddy's little girl, and he was like, my idol."* Anna's father was head of the family home-business. Anna's Dad had handled virtually every part of the business with Anna and her brothers helping only peripherally. This meant that with the father's death there was chaos in the family as well as tremendous grief.

Just two years after her father's death, and two and a half years after her diagnosis, one of Anna's brothers was hospitalised for depression and two months later died mysteriously under care in a mental hospital. A high school friend of Anna's died from cancer during the course of

Anna's involvement in this research, leaving a husband and young child. After re-living this series of losses, Anna expressed her frustration in this way:

> *... To me, as far I feel, truthfully and honestly, I feel life in general is hopeless... you try and try and can't get anywhere... losing too many people, who die too young, way too young... How do you tell somebody 'life goes on, it gets better? Because it doesn't seem to as far as I'm concerned...*

Anna's Experience of Hope

> *... HIV is always there and it just changes your whole life totally. I mean, you can go places and do things, but it's like, 'okay', I'm having a good time now, oops, look at the watch, it's time to take my medications...it's there, you know? HIV is just always there...*

Shifting Identity

When Anna received the test results confirming HIV infection, a process began involving a shift in identity. Beginning with the recognition that life would be different and that she herself was "different", that is, someone living with HIV, Anna needed to redefine who she was. Thinking only that "other people" got AIDS, it became necessary for her to look at herself and her life through a different set of interpretive lenses. This revelation of 'difference' may be instantaneous or it may take place over a prolonged period of time, but it is a common occurrence among those infected with HIV/AIDS (Keen, 1994; Mtousek, 1994). The revelation of difference may be true for many who receive a diagnosis of any kind such as cancer, bi-polar disease, or schizophrenia. However, because it is overladen with stigma regarding sexual or drug using behaviors and because it is linked with AIDS and certain death, the time of diagnosis can be particularly momentous for those with HIV summarized by Keen (1994) in these words: "I am different":

> *... when this virus becomes a formal part of you, your identify shifts. In the same way that having a ring slipped on your finger serves to tie the knot, acknowledgement of HIV renders peaceful cohabitation with this strange bedfellow a necessary, everyday affair* (Mtousek, 1994 p. 106).

For some (including the author of the previous quote), a diagnosis of HIV poses the ideal predicament allowing an individual to alter lifestyles, commit to social activism, explore one's

spirituality, and re-examine or seek clarity in relationships with others. Phrases like, "HIV has saved my life; I would have been dead if I hadn't changed my behaviors" and "I've certainly learned to appreciate life since becoming infected" are common in deep conversation among persons living with HIV/AIDS. For some however, HIV presents more than a physical threat; it can challenge the very ground of one's emotional existence. Without the emotional or spiritual resources to move through the initial shock and despair, one may be unable to embrace the shift in identify, and the changes in perspective that change entails.

Anna graphically describes her reaction to her diagnosis:

> *... I was hysterical... totally freaked... and I was so worried that my Dad would look down on me, thinking I was cheap, and that I just laid around with every Tom, Dick and Harry or did drugs or whatever. Because before I was educated about HIV, that's how I thought it came about...*

Still in the midst of insufferable grief and reeling from the series of events over the past few years, it was difficult for Anna to talk about hope and to access the experience of hope. Raised in a middle-class family far removed from urban problems, Anna shared with me that she had been sheltered from much of life's hardships. Attractive, Caucasian and heterosexual, Anna had never experienced any form of prejudice directed toward her before she became HIV infected. She had always been energetic, happy, and healthy. These personal challenges, the death of so many close to her and the emotions and losses associated with HIV left Anna broken-hearted and bewildered. Without her father, the centre of the family, "[her] rock", Anna was lost without *her own* centre, without her hope. Consequently she was unable to adapt to and absorb all the changes and challenges of the recent years.

Remembering only what *was*, Anna was unable to integrate the realities of the present or face the uncertainty of the future. For Anna, the experience of hope was difficult to access because her initial "hysteria" was still with her. In fact, Anna stumbled over the word hope:

> *... Well, [hope] is positive I know that! But it is confusing too... I don't know... I think of it as a religious thing, because that's where you hear about it the most... I mean, I went to a wedding recently and the word was used over and over a thousand times in the*

service... but what's the difference between a wish and hope? I really don't know, maybe you should tell me! I do know this: It's just too hard to talk about hope because too much has happened...

Anna found it difficult to talk about hope because *"too much has happened"* namely, the diagnosis of HIV infection, the death of her father, her brother and her close friend. This succession of losses would present challenges to most anyone. Coupled with the illnesses associated with HIV disease, and the changes in her lifestyle and work, Anna's entire world was shattered in a short time. Caught in a spiral of grief, separation, and loss, Anna's own diagnosis with HIV became enmeshed with all her feelings surrounding the death of her loved ones and the ensuing turmoil regarding the family business. One loss on top of another became one loss inseparable from another. Consequently Anna named hopelessness as linked with two major crises: *"When I found out I was HIV positive and the day my Dad died, those were my two major hopeless times."*

Throughout our conversations, Anna's thoughts about hope moved from her present frustrations to thinking about the past, when life was *terrific* and she lived *without a care in the world*. At the same time, Anna repeatedly dreamed about the future and often yearned for a cure for AIDS. At one point, frustrated with the ongoing regimen of pill taking, Anna stopped her medications, trying to ignore the presence of HIV. Immediately her blood counts shot up sending her Doctor into a frenzy. Anna did not share with her physician that she may have been responsible for the dramatic rise shown on her results. Feeling a bit guilty and sneaky, Anna began taking her medications faithfully. The following scene took place soon thereafter, which Anna shared as an experience of hope:

...My last Drs. Appointment, when I got my test result back... [was an experience of hope]. Well, there I sat, and I was so scared, I thought for sure after that last time – remember I told you I had stopped takin' my meds and my viral load shot up? Well, I was so scared. I thought maybe the Dr. would say I have AIDS and I was petrified. I live in fear of that... And I had started takin' my meds since that last appointment. So there I sat, just waiting... I was just hoping that everything would be OK. And the Dr. came in with my test results and as soon as I saw her face I knew... [giggles]. She was just smilin' and she started laughin' and she said guess what? Your tests are good! And so I just started

laughin' too and there we were, in the office just gigglin' and laughin'... I think she was as relieved as I was after that last test... (she still doesn't know I stopped takin' my meds then, I think she thinks SHE did somethin' wrong...).

When I asked Anna what that was like, she responded:

... It felt great, just like the virus didn't exist no more. It was like, yes! maybe there is that chance, maybe someday... maybe someday there will be that cure out there...

There's No Place Like Home

In the film The Wizard of Oz (Fleming, 1939), a child named Dorothy ends up on a strange journey toward a place called Oz. Young Dorothy's mantra (and consequent link with reality) throughout her ordeal is the simple phrase uttered prayerfully, wistfully *"There's no place like home, there's no place like home"*. The repeated expression of this phrase engenders a sense of compassion for the character; the viewer feels the pathos of a child yearning for her home and family. At the same time, the phrase gives voice to that which has inspired Dorothy, giving her courage and conviction to go on in spite of her difficulties.

Anna's yearning is similar to Dorothy's, for the past presents a wistful recollection of what was. The impossibility of returning to the past is overshadowed by the desire to "go back" as if the yearning itself could erase current realities. When asked about a time of hope, Anna longingly remembered those times before HIV:

... my biggest thing would be to go on the way I used to be... when life was normal... I was popular. I would say I was the most popular person around; I'd date... there was never a weekend that went by that I didn't have a date... I used to laugh and carry on... I didn't have a care in the world... I used to have ambition to do things... I was a happy person; I'm just not like that anymore... I'd just like life to be normal again...

Life had changed since she learned of her HIV status; but Anna had neither accepted nor integrated the changes. Instead, Anna yearned for life to be "normal" again – like it was before the realities of HIV infection, and the losses in her life since the time of her diagnosis. Anna yearned for something outside her reality: those moments in her past when she *"didn't have a care in the world"*. Her yearning for the past was intimately tied in with her experience of hope; indeed it was the measuring stick against which everything was compared:

...I know I never thought about hope before HIV... and I still don't know what hope is but I can tell you what I hope for... I hope for a cure... to have a normal life... to date and have a family... to have energy, fun, happiness... to have life be the way it used to be, when I didn't have a care in the world...

Somewhere Over The Rainbow

Anna described her present life as a time of drudgery:

...you try and you try and you don't get anywhere... How do you tell somebody 'life goes on, it gets better?' Because it doesn't seem to as far as I'm concerned... I do know what I hope for... I hope for a cure [for AIDS]... to live a normal life... to have energy, fun, happiness...to date... to have life be the way it used to be!

Before her ordeal in the fantasy world of Oz, Dorothy dreams of a wonderful place far away from her dreary farm life in Kansas. In the movie version of the story Dorothy longingly sings the melodramatic song, "Somewhere Over the Rainbow." For Anna, the present is unfamiliar and confusing. On one end of the spectrum stands Anna's past, what used to be 'before' HIV and before the losses of her brother, father, and her close friend. The time 'before' is represented by the phase *There's no place like home*. On the other end of the spectrum is Anna's dream/wish for a cure for AIDS and for life to be "normal again". This time is represented by the phase *Somewhere over the rainbow*. Situated in between the two extremes, Anna is at once petrified and immobilized by the dual realities within which she lives. The past is over; her life will never be the way it used to be and her future is uncertain (except that the future will bring more loss, pain and endings if not death). The present is a time 'in between' the past and the future. This time 'in between' is unwelcome and unfamiliar; it is uncharted territory for Anna, and she has yet to find her way.

Anna's photos

Anna knew immediately how she would utilize the camera. She laid it aside for use during a long-awaited trip to Colorado. She was completely disinterested in taking photos around her home or in the context of her daily living because Anna *"...just knew the trip was going to be wonderful and I wanted to save the camera for that trip."* Anna used the camera for this project

and was intentional about taking pictures that reflected her experience of hope. Still, she waited to take pictures of her trip as if nothing around home could represent an experience of hope.

Included in the assorted pictures taken in Colorado were pictures of the friend with whom she visited *"... because she's the one that drove back from Colorado with her two little kids when my brother passed away just to be with me. There's just a special bond there."* In reference to another picture of her friend Anna said, *"This is hope because when I look at her I am reminded that there are good people in the world, special people in the world. There's loving people in the world..."*

Anna also took many photos of her friend's life: the friend's children and husband, the husband and wife together, and her friend's house and flower garden:

> *...I was kind of a little jealous because all my life, in my heart I was hoping I could have the little house like my girlfriend's; so it was kind of a lost hope because I know deep down I'll never get that little Cape Cod [house] in a country setting on a hill with a little wrap around porch; which is what I always thought...*

Anna was particularly excited about her pictures of the Rocky mountains in and the blue skies surrounding them. She was awe-struck by the beauty of the massive peaks contrasted against the brilliant sky. The majestic scenery *"... was my favourite part of the trip... feeling so close to the sky... it makes you feel so close to the ones that aren't here."*

A Snapshot of Hope: Anna

Colorado is so great! I mean, we think we have mountains in Pennsylvania! These are really mountains! I've been looking forward to this trip for a long time and I am just glad I'm not too sick to be here. I've been really down lately, wondering if it's all worth it, but I've had this trip to look forward to. I like being away from work and my worries and all the secrecy around the HIV. It's good to forget about it... even though I can't totally get it off my mind. Just when I'm having fun and life seems normal again its like, oops, there it is; time to take the meds again. So I can never really forget about it. Can't life just be back the way it used to be, before all this, when I didn't have a care in the world?

I brought the camera along that Carol gave to me. I took a couple of pictures with it, like I took a picture of Cheryl's house and her child and the two of us laughin' like two little girls. Cheryl and I are having a fantastic time. We've been laughin' and partying and carrying on ever since I arrived... just like old times! She is a true friend... we can talk about anything. We laugh all the time and we can also cry together. She's not like other people that you can't trust, she is a true friend. I know she'll be there for me through thick and thin!

But I just had to take this picture the other day. I mean, here I am in Colorado with those gorgeous mountains all around, everywhere you look. Cheryl and I were driving down the street. Just when we came around the corner I said to her, 'stop, stop the car!' Up ahead was this mountain with blue sky behind it. I'm tellin' you we do not have that kind of blue sky around here! I mean it was blue... just like the colour of my Dad's eyes – that kind of blue! But there's the mountain with snow on the top and the sun shining on it...it was so bright up there, like a dream, or a painting! There were just a few clouds hangin low and that mountain peak coming right up and the sun shining on it. I said to C., 'I've got to take a picture of that!' and so I took three pictures right then and there. It was like... perfect... makes you forget your troubles and think anything is possible! Maybe there is a cure out there...

When I looked at that mountain it was like, heaven... I said to my friend, 'that's where my Dad and my brother are... and that's exactly where I'm going to go.' And we just sat there and we balled, we just cried... I thought, 'I hope when I go that's what it's like... so awesome and free'... I really do, just beautiful... I imagine my Dad and my brother and others who have died are somewhere just like that... I'm hoping it's going to be as beautiful as those pictures are and as peaceful as those pictures are...

A Representation of Anna's Experience of Hope

Anna's experience of hope is depicted in Figure C. Anna experienced hope in her recollections of what was and what 'could be'. Hope was experienced as part of a distant past, when life was carefree, her family was intact, HIV was someone else's problem, and the future was full of possibility. Hope was also experienced as distant and in the opposite direction, somewhere over the rainbow, where there just 'might be' a miracle: a cure for HIV/AIDS. The arrows in the diagram represent Anna's yearning hope, pointing both to the past and to the future.

Figure C: A Representation of Anna's Experience of Hope

Vanessa

"The sunrise [shows me] that I got through another day . . . and that's hope!"

An African American woman in her late thirties, Vanessa greeted me as if greeting an old friend. Visibly weakened by her illness, and moving with difficulty, there was an aura of dignity about her as she invited me into her home. As we settled down to talk, Vanessa apologized for still being in her bathrobe and for not feeling well enough to straighten up the house. I commented on the framed photos on the wall and Vanessa told me about each of them: a daughter who had recently graduated from High School; a son still attending High School; her husband and their other daughter, Vanessa's eldest.

As we sat and talked, Vanessa shared with me some of her past and the events leading up to an AIDS diagnosis. For many years when her children were young, Vanessa had struggled with drug and alcohol. Vanessa said that *"with God's strength and a lot of willpower"* she overcame her addictions, staying clean and sober and holding down a steady job. She was certain that she became infected with HIV through drug use even though when she was diagnosed with AIDS she had already been drug-free for some time.

Vanessa talked candidly about the time of her diagnosis. She had been extremely ill for a number of weeks and had lost a lot of weight, saying, *"I was like down to eighty-two pounds or somethin' like that."* Along with the weight loss, she had been exhausted, repeatedly visiting her physician about the symptoms. Vanessa's complaints were treated casually, as the doctor attributed her fatigue to the fact that she was working two jobs, seven days a week. Insisting that something had to be done, Vanessa finally took charge: *"I said to that doctor, 'no, I am not just tired. You're wrong. I'm going in the hospital, I don't care what you say!"*

Vanessa was admitted to hospital and was eventually diagnosed with pneumosistis pneumonia. At the same time, blood testing confirmed the presence of HIV. The combination of HIV and pneumosistis gave Vanessa an AIDS diagnosis. Consequently Vanessa first learned she

When you said hope I thought of hopeless and then I guess. . . yeah, there is times of hope, cause I'm not in a place of hopelessness anymore." She continued by saying, *". . .I don't know, hope to me. . .I don't know, I guess, I get my strength from God."* I asked her about hope and she replied using the word strength; hope was equated with strength. Vanessa's use of the word strength, although spontaneous, appeared also intentional, as if she used the words interchangeably.

Vanessa believed that her upbringing in a Holiness Church "instilled" in her a firm belief in God, providing a firm foundation to which she could return: *". . . I'm glad they installed in me a belief in healin', and in God 'cause I knew to go back to it to get my strength. . ."* When asked to elaborate, Vanessa stated matter-of-factly that without God giving her strength, she'd be out *". . . drinking or getting high or whatever to suppress what I'm goin' through"*. Without 'strength' Vanessa said she would fall back on her life of addiction, suppressing the feelings and realities she faced.

Vanessa told me she wasn't sure she ever thought much about hope before AIDS, and quickly added: *"I'm not sure I even thought much about hope ever."* 'Hope', Vanessa said, was not a word she used much at all. When I asked Vanessa to share an experience of hope, she paused for just a moment and then said, *". . .when you first said 'hope' I thought of hopeless. . . and then I guess, well, yeah there is hope! There <u>have</u> been times of hope, cause I'm just not in that place of hopelessness anymore."*

<u>Getting Up And Out</u>

Despite not *thinking* about hope, Vanessa *experienced* hope. She recognized the experience after recalling what she referred to as the 'place' of hopelessness. After receiving the news of her AIDS diagnosis, Vanessa went through a period of time during which she shut down, not wanting to leave the house or talk to anyone. She felt alone and wanted to be left alone. She had no desire to take part in day-to-day living. It was a time of hopelessness. But something changed. Over time, Vanessa no longer felt ashamed, alone, and without energy; she was no

longer dwelling in that place of hopelessness. In fact, Vanessa described a dramatic turnaround, remembering precisely the movement out of hopelessness. She continued:

> *...After awhile I guess I realized I wasn't gonna die and so I might as well start tryin' to live ... while I'm here... while I'm able to... so I got up and out of that place of hopelessness... no more hiding in shame or in darkness anymore... Oh believe me, I can get to that place sometimes; some days I'm just like, 'damn!' So I know then I gotta do somethin' or I just feel hopeless...*

Clearly there is movement and action in what Vanessa described. First is the realization that she is experiencing hopelessness. Next is the resolution to do something. For Vanessa, getting *up and out* is a definitive act – something she *does*. Like climbing a ladder from the depths of a deep hole, she pulls herself up and out of that place of darkness/hopelessness.

When asked what the experience was like, Vanessa replied, *"I don't know... It was kind of like, OK God, get me out of this; I need the strength. And then, there I go, I'm not gonna stay in that dark place no more!"*

Giving and Getting Hope

Vanessa said, *"I get my strength from God."* On the one hand, strength came from within *(I'm not gonna die so I might as well start tryin' to live).* On the other hand, Vanessa gets strength from God. When I asked her about this it became clear that Vanessa reached out to God—or others—in order to 'get' hope when she needed it. She sought out one friend in particular, another woman who was also HIV positive:

> *... every now and then I'll go through a thing ... and [my friend D.] is the one who gives me a lot of strength. One time I called her cause my T-cell counts were all down and shot to hell (I had like ten T-cells), but she was just feeling great, she was doing real good and she was telling me, 'girl, I had none [T-cells]! They couldn't find any! And even though they couldn't find any I just kept tellin' myself, I <u>had</u> to have one hiding somewhere. They told me I had none and I'm still here... I mean come on... ' So she gave me a lot of hope. She gave me a whole lot of hope...*
>
> *It sort of was like well, OK she did it. She got to where she's at and she's still here. I can too, you know? I just have to get a hold of whatever it is she got a hold of and <u>apply</u> it!*
>
> *Now, she has it a little different than me, like I say I get a lot of strength from the church and God and she's not into that... so it's somethin' different... like a positive*

attitude: positive, she was just positive about a lot of things, you know. . . I think a lot about that ... because you know, I'm still living... OK she's been doing good six or seven years and all that, so I can too... It's a positive attitude! Like, now I got it and sometimes I give it back to her. So every now and then D. gets down in the dumper and I say, 'all right D., now it's my turn... come on now'... and so I give it [hope] back to her...

For Vanessa, hope is intentional *and* it comes as a surprise. Prayer, phoning a friend and/or making a decision *"I'm not going to die so I might as well start tryin' to live"* were practical and concrete actions. But these acts were not done with the end goal specifically of achieving hope. There was no simplistic formula in undertaking these actions; nonetheless, hope was experienced within the context of these actions.

Just as hope could be *given,* so hope could be taken away. For example, when Vanessa's father was dying with cancer, Vanessa tried to give him hope/strength by giving him scripture passages and meditation tapes *"... like people did for me when they pulled me out [of sadness or depression]."* Vanessa's sister, however, had a different attitude about their father's situation. Within earshot of their Dad the sister proclaimed, *"Well he's not living a quality life and he's not going to live."* Vanessa was troubled by this and believed her sister's comments *"put it in Dad's head"* to give up. For Vanessa this was abominable: *"[She said these things in front of Dad] and I'm thinkin', 'What?!, You know!? I'm tellin' you, he's living, you know what I mean?!' To me as long as he's living there's hope!"* Vanessa believed that her sister's words prompted the change in their father's condition because shortly thereafter their Dad told Vanessa that he wasn't sure he'd live much longer. Vanessa responded by saying *"Dad, that's your decision and I respect that but I hope nobody put that in your head."* In a short while, the father died and Vanessa was certain that he died because his hope had been taken away. Vanessa's tone of voice as she talked about this event conveyed both anger and defiance.

On another occasion I asked Vanessa to share an experience of hope. She was quick to recount a recent visit to her doctor's office for routine blood-work.

... O.K., I can tell you about an experience of hope... when my viral load came back 'undetectable'... you see, the viral load had been going up and down for I don't know how long and I was so frustrated! Well, my doctor had been changing my medications for a few months and that viral load was up and down and then it started going up and up and up. I was like, O my God, what am I gonna do it's risin again and I started to feel like, the heck with it... Then the Dr. changed my meds again. I didn't want to change them at first but he changed them and I started taking them and the viral load started going down. Then one day I was in his office and he came in, just like usual, to go over my blood-work and he said, 'Well, it's undetectable'. And I just felt great! I said right out loud "Thank you Jesus!" [she is giggling here] I was like, ... Yes!... [laughs]... I couldn't wait to get home to run to tell everybody... my Mom and everybody, 'hey, I got some good news for a change!' I went and called everybody and anybody and I was like, hey, guess what?! Yes I did, I felt good, I don't know, I guess... I thought, 'God answers prayers, he really does'... it felt good, it felt good... almost like the virus didn't exist...

Prior to this check-up, Vanessa's blood-work had been erratic, going up and down and up and down. Consequently, her expectations were low and she was prepared for news of any kind. When she heard the word 'undetectable', there was a sense of relief coupled with a momentary suspension of reality: *"It felt good... almost like the virus didn't exist."* With great emphasis Vanessa felt as if her prayers had been answered. She was animated, giggling and laughing right out loud as she told me this. Her face was radiant and she nodded her head slowly from side to side, savouring the recollection.

Vanessa was under no pretense that AIDS would go away. In fact, on the day she shared this experience, Vanessa was feeling sicker than usual and was coming to terms with the loss of vision in one of her eyes due to cytomegalovirus, an AIDS-related complication. Nevertheless Vanessa's experience of hope was experienced as this moment of elation: prayer (something she *did*) was answered (something *given*) to which she responds outwardly by saying *"Thank you Jesus."* Unlike the experience of hopelessness, which is borne in isolation, *this* experience (of hope) was to be shared: *"I couldn't wait to tell everybody... and anybody."* That moment of receiving good news (for a change) didn't erase all that had come before or may come after, *"[it was] **almost** like the virus didn't exist."* The moment did offer a respite however, and at the same time, a spark of vitality.

Vanessa's photos

At the conclusion of our first conversation, Vanessa willingly accepted the camera and the journal, even though there wasn't a hint of enthusiasm over the journal. When I asked about the journal in later conversations, she relied sheepishly, and with some guilt, *"[giggling] No, I didn't even write in it... I thought about it a couple of times, and just some days it would be in one place and I thought, 'Oh, I'll go get it and write and I never did get back to it... maybe I should take it with me to church one day..."*

Vanessa had taken only a few of the twenty-four photos available on the roll, and at least two of those photos did not turn out well. Before talking to me about the photos she did take, she described an experience of hope and a photo of a sunrise she had wanted to photograph but she had been too sick to go and find the camera at just that moment.

Vanessa spread the photos out in front of us and spoke first about a photo she had taken of her teen-aged children with their grandmother, Vanessa's mother:

> *... my family, because they are the ones that made me want to try to go on after I found out [about AIDS]... they gave me hope in some way because I felt like I had to keep going because of them... they were supportive, and my kids... you know, just by being there I guess. I felt I had to keep living for them, you know. One of the first things my daughter said when I told her was, 'What about us?' and I said to her, 'Who said I was going anywhere?' Whereas before that you know, I had been thinking, I'm gonna die... so I had said to her 'Who said I'm going anywhere? I'm still here. We'll beat this, I will be here until you graduate!'... and she was like in ninth grade... and now she did graduate!*

Vanessa had also taken a photo of an old picture, taken of her children when they were quite young: "*...That was way back [because] they were my... they were sort of my strength then. Well more like a reason to find strength or hope, you know?*" Vanessa's pictures also included the following: a Bible; Jesus on a cross; her pills' and the clock hanging on her living room wall. In reference to the picture of the Bible, Vanessa said, "*... and of course I believe in this, the Bible... well, the words in it... I believe in that, you know? That's what gives me hope, too.*" This comment was followed by the picture of Jesus on a cross (a wall-hanging), about which Vanessa said, "*... My faith gives me hope. I don't know; It's like it's HIS strength that I can beat this... It*

gives me a peace of mind... I can't even explain it; I don't know how to explain it. But it gives me some sort of peace. This is my strength."

For one photo, Vanessa had set up eight to ten vials containing her prescription medications, quite an assortment of shapes and sizes. Some were protease inhibitors to fight the HIV. Others were to combat the cytomegalovirus (CMV) which had already caused blindness in one of her eyes. Other medications included those to alleviate the side effects of Vanessa's *other medications*. Vanessa had this to say about that photo:

> *...And here we have these pills. That's sort of my way... that's sort of hope too. It's something that seems to be working and things have been pretty good. I had a pick line and I just got that out a month ago. So that was good news that it came out. And my eye is doing better. The pills seem to be <u>something</u> that's working.*
>
> *I remember too that I wouldn't even take 'em. I thought, 'I'm not taking any more damn pills [I suffered from so many side-effects] they do more harm than help'. But they actually, you know, my viral level went down with this cocktail. I'm taking three at a time and then these other ones for my CMV. Other than that, things have been pretty good. I'm more accepting than I thought; Before I used to talk about it and I thought I was going to cry and you know... I can talk about it now...*

The final picture Vanessa talked to me about was the picture she took of the clock on her living room wall. Time was important to Vanessa for these reasons:

> *...as time went on I realized it was all together in time [the Bible, Jesus, and herself]... and instead of feeling hopeless, I realized that I could still go on... That's why I know when the sun rises... you know, it's like hope. Everyday I wake up in the morning and I know it's another day and I'm still here... and that's hope!*

<u>A Snapshot of Hope: Vanessa</u>

Sweet Jesus what a night! Oh no, here we go again! Now I have to drag myself out of this damn bed and go to the bathroom again. I just can't keep nothin' down these days. Anything I eat comes right back out—one end or the other! It's been a long night. My husband and I aren't talkin' again and I don't have the energy to deal with him not when I'm feelin' this sick and low. Even with that big man sleepin' right next to me, it just feels like I'm all alone.

And when I feel like this I can't stop thinkin'. The darker it is, the more I think about everything: bein' sick... my Dad dyin... losin' my eyesight... my friend's being sick... and those damn T-cells... What good is havin' ten T-cells anyway? I'm tellin' you I don't feel like leavin' this house today. God when I feel like this I don't want to see or talk to nobody! I'll just stay here in the dark.

I might as well go downstairs and wrap myself in that old blanket for awhile. Maybe what I need to do is some prayin'; that is where I get my strength. Maybe I am just not prayin' enough

these days... I need that tie, you know? That strength that comes through prayer... I always feel worse when I'm not prayin'...

It's the same as I feel when I talk to D. She really brings me up out of the dumper. She's got like, no T-cells and she's doin' real good... real good... and she's been doin' good for a long time. She called me yesterday; God that girl has got some attitude! She gave me a Scripture passage yesterday, now what was that? The same one they preached on last week at church... faith is... hope is... the assurance of things... not seen... that's it. Sweet Jesus, give me strength... I'm not givin' up, that's all. If she can do it so can I. I just got to get a hold of what ever it is she got and apply! And here I am sittin' in the dark, feelin' sorry for myself...

There's that ol' sun comin' up again... imagine that! I can see some light comi' in the window...even with my eye goin' bad I can see that light...Good, seeing that light means I got through that long night, and I'm not dead yet. I'm gonna pull up that shade and see what's happenin' out there... well I'll be, just look at that light... even those ugly buildings across the street almost look good with that mornin' light on them...

Hey where is that camera Carol left for me? I want to take a picture of that sunrise, I really do. Seein' that light means I made it through another day and that's hope! I guess I might as well get up and out of this place while I still can... Hmm... I wonder if D's up yet... maybe I'll just call her up and tell her about that light out there... and that I'm not boo hooin anymore... just in case she's feelin' low today!

A Representation of Vanessa's Hope

Figure D depicts Vanessa's experience of hope. For Vanessa, hope is something we get when we need it; it is a combination of mental attitude and inner strength. Further, hope can be taken away from an individual or given away to others who need it. Vanessa gets hope from other people (her friend in particular), or through prayer and her relationship with God/Jesus. Consequently, Figure D portrays a second figure. That person is not clearly defined in order to represent Vanessa's inner self, God, Jesus, or a person who may be instrumental in giving or receiving hope. The arrows portray the action orientation of Vanessa's hope. Her description of hope as getting "up and out" (of the dark place of hopelessness) is represented by the raised figure, and the arrows moving upwards.

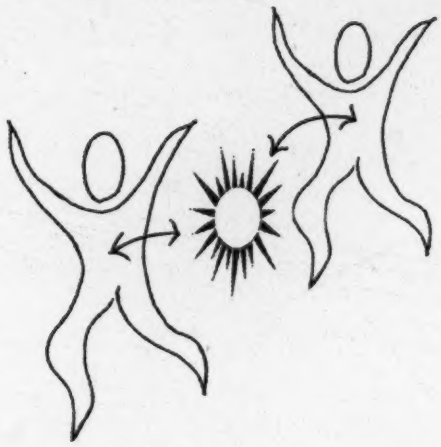


Figure D: A Representation of Vanessa's Experience of Hope

Grace

"...I love to see the sun shining through my house, in the morning, when it's bright...almost too bright. I don't know...It kind of gives me hope...that there's a new day...and that life goes on..."

Grace was a vivacious young woman who shared her story enthusiastically. She talked easily about her hope, HIV, and her (Christian) faith. The first time I arrived at her small cottage, which Grace rented from her parents, I noticed at least two cats peering at me lazily from the driveway and was greeted at the door by an exuberant five-year-old girl clutching a squirming bunny rabbit. The child bore a striking resemblance to her mother although her skin was a few shades darker than Grace's. Grace welcomed me into a sunny cozy kitchen while she gently coaxed the child to put the bunny back outside and talked her into watching a video. While Grace was in the other room I looked around the kitchen where we were going to meet. It was spotless and bright, with potted plants on the windowsill, framed religious quotations hanging on the

walls, a calendar (each day crossed off in red pen, and a neatly arranged message center near the phone. Among the items was a 'to do' list with half of the items checked off.

As we settled at the kitchen table, Grace sat down across from me and started talking immediately: *"I'm a little nervous about being taped, but I'm also excited. I was telling my friend about this project and I think it's really neat... and very important. If we can help other people, that's all that matters!"* Grace looked over the informed consent form carefully, asking questions of clarification on a number of points. She was especially concerned about the use of her name and issue of confidentiality. At the time our first conversation, Grace had only know about her HIV status for a few months, and was worried about the repercussions for her daughter within the community should the truth come out.

The conversation began with Grace recounting the events leading up to her test results. Grace had been dating a man who was not only abusive but who had a criminal record of abuse. The relationship was so abusive that Grace had a restraining order placed on him. After only a few days the man violated the restraining order and was sentenced to time in prison. Grace began to hear rumors that the man was HIV positive and, at the urging of a coworker, Grace agreed to go to the local clinic for an HIV test.

Early in the summer, Grace went to a clinic near her place of work. Although worried about confidentiality, the proximity of the clinic made it convenient for Grace to return for the results in the required two weeks. Grace said that she intended to pick up the results on schedule, but kept "forgetting" to do so. Just prior to leaving for a holiday at the end of the summer, Grace decided to return to the clinic one day during her lunch break: *"I just ran over there to get the results and I was coming right back to work."* At the clinic, Grace was told that she tested positive for HIV. Dumbstruck and not knowing what to do, Grace spent the next few hours at the clinic in tears. When Grace left the clinic she drove herself back to work. Alone in her vehicle, her feelings were jumbled:

...I had been crying for like, three hours at the clinic and I got in my car and I was still sobbing...I remember saying to myself, 'why did I even get tested/ I'd rather not know.' Then I thought, 'well, I don't have to tell anyone. I'll keep it a secret.' I guess I was in shock. Then, I don't know, I guess I was more panicky thinking, 'I'm going to die, next week or next month. 'I was just, like, pretty much of a mess...

Grace left for her holiday at the shore the next day. In spite of her worries, she kept her feelings and her news hidden from her best friend, with whom she was traveling.

...I didn't know how long I would, you know, I'd stay alive or how long I had. And we went to the shore and I was afraid to tell [my friend] and I just remember walking along the ocean by myself just crying and crying, just thinking about everything. It was constantly in my head...and I was crying, you know, saying, O God, take care of my daughter...I was hopeless...in total despair. I was like, well, if I don't die right away from the HIV, I just want to die anyway. I wanted to give up right then and there, you know? I didn't think that I was going to live much longer. I didn't want to live... I look back and I can't believe how depressed I was...

A social worker with a university education, high energy and great determination, Grace was used to being in charge; but the HIV positive test results left her feeling completely out of control. Her initial response to the HIV infection was sadness and depression. Soon, however, Grace felt a strong desire to take control and fix things. After returning from her holiday, Grace fell into action:

...So, when I came back from the shore I began to make sure everything was taken care of. My next thing was, 'Okay, what am I going to do if I'm gone, to take care of my daughter?' I'd been meaning to make sure that she's taken care of, so I called my sister...Then I called the couple who helped me so much when my daughter was born. He is a pastor and so I guess I was planning my funeral. I asked him if he would do the service... next I thought, 'I might as well quit school...

Grace made arrangements with her sister's family to assume guardianship of her daughter upon Grace's death and she planned her funeral. Next, she began giving meaningful things away and held a yard sale in order to dispose of unnecessary items:

...I was frantic, thinking I'm not going to need this, or that, so I started cleaning house. At the time I didn't know the difference between HIV and AIDS, I had no clue. I just thought, I'm going to die, I have AIDS. So, I started getting ready to die...

After this time of frenzy, Grace decided she needed to learn as much as possible about HIV. She spent a lot of time on the phone taking advantage of the anonymous 24 hour toll-free

National information lines. She also enrolled as a client at an AIDS Service Center in another community, in order to maintain her confidentiality locally.

The stress of keeping the secret of her HIV status took its toll on Grace.

> *... I would be crying on my way to work, crying on the way back and it was terrible... my daughter would say 'It's O.K. Mommy, why are you crying?' and I didn't even realize I was crying... I was miserable... and even though we are all close in my unit at work, no one knew how depressed I was...*

While at work one day, the tension was just too much for Grace to handle. A co-worker had been relentlessly complaining about her own sadness over a pending divorce. This had gone on for some time, but suddenly Grace was pushed to the breaking point. Unable to hold back her frustrations, anger, and tears, Grace exploded, divulging her secret in the process. Grace told it to me this way:

> *... This woman at work was going through a divorce, and they had adopted kids and everything and it was sad. But she had been moping around at work, and whining and crying and getting all kinds of sympathy for, like, a really long time. Finally, one day she was moping around and I couldn't take it anymore and I basically just yelled at her. I started crying and yelled, 'you should just be fricken' happy that you are alive!*

When she finally admitted the cause of her outburst (that she was HIV positive), Grace's co-workers responded with love and support.

Grace received a mix of responses from others when disclosing her HIV status. Concerned for an ex-partner's health, Grace informed him so that he might choose to get tested. That man disclosed Grace's status to another man before Grace herself could talk to him. That second man happened also to be the father of Grace's child. Grace sighed when she told me this, pronouncing this understatement, *"....So, that really didn't help things... at all!"*

Grace's family displayed a wide range of reactions in response to the news. Some of her family members were born again Christians who believed that AIDS was a punishment from God for Grace's "illicit" behaviors; and they told Grace so. From those family members Grace heard harsh words of bigotry and hatred. Most of the others were supportive except for one brother, a pastor of a fundamentalist church. Even months after her diagnosis, this particular brother was

relentless in his condemnation, phoning often just to rail at her. During a recent phone call he had brought Grace to tears saying, "God is punishing you for having sex and not being married! You deserve to get AIDS! It serves you right for going out with a black man! You are going to go to hell." The words and attitude behind the condemnatory words both hurt and perplexed Grace. A deeply religious woman herself (and also inclined toward fundamentalism), Grace said to me *"It always helps me to pray; I feel closer to God. I mean, I just can't believe God really hates people with AIDS..."*

Grace's parents remained quite involved in her life, helping with Grace's daughter, providing financial and other day-to-day help when needed. While helpful and supportive in many ways, Grace's parents nonetheless repeatedly voiced their disapproval regarding the child's father and some of Grace's life choices. Soon after Grace became HIV positive, Grace's mother was diagnosed with cancer. After that, much of the family concern was directed toward the mother's illness. Grace had just started dating another man at the time of her diagnosis. When she told him that she was HIV positive, he simply held her for a long while as the two of them wept together.

Grace's Experience of Hope

A Matter of Control

When first asked about an experience of hope, Grace needed clarification on the question. Her response was, *"Do you mean hope for the future or hope for the disease?* I simply urged her to say whatever came to her mind. Grace said briskly, *"I hope for a cure... a vaccination... to have another child... and relationships..."* When I asked her to tell me about a time when she felt hope, Grace mentioned her physician's use of the word 'hope' and the impact this had on her:

> *...My Dr. actually used the word hope. He said to me, 'A year or two ago I wouldn't have said that there was any hope or wouldn't have felt that there was much hope, but in the last year or two there's a lot of hope that this [HIV] could be a chronic illness rather than a terminal disease.' So now I look at it like, what kind of things can I do to stay healthy and to be able to keep living as long as I can?*

Grace did not immediately experience a dramatic life change. Neither did she turn to drugs or alcohol to ease her pain. She did however respond to the words of her physician, experiencing those words as "hope". Her reaction was consistent with her propensity to take control of a situation. The physician's words took hold, setting off something within her, sparking the impetus to gather more information about HIV:

> *... So I set out to learn as much as I could about HIV... I knew nothing as I told you... What really helped is that I utilized the 1-800 numbers. I looked them up in the phone book and called the Pennsylvania number, the national hotline and the CDC hotline. I asked all kinds of questions, even the dumb ones I had you know, that I thought were really stupid, I could ask them because the people on the phone didn't know who I was...*

Hope, for Grace, seemed to center on maintaining a locus of control. She related hope to action, being able to do something in response to a crisis situation. Spurred on by her physician's words, Grace chose a plan of action, which became for her an experience of hope.

> *I know someone who used to do drugs all the time... shooting up and everything. They won't do anything because of HIV. They know they have to stay healthy because of this disease... and so the flip side is it makes people think about things a little bit more... not that HIV is good to get, but it's actually helped change some people's lives for the better... you know I was in the hospital for a week not long ago... I was getting sick, I was getting diarrhea, like for three months straight. And, I was losing some weight too and they didn't know what it was. So we lowered the dosage of my dedication and it's helped. I know I need that medication. And so I'd say I'm much more hopeful since I've gotten treatment and since I've gotten the services, whether the individual, the group, or the support systems out there...*

As I re-read the transcripts from the first conversation with Grace I was aware of the lack of focus and my inability to keep hope at the center of the conversation. Grace shared lots of information, talking openly about her life situation. She spoke quickly, changing thoughts often and it was difficult to keep her focused on hope. She seemed almost preoccupied, her thoughts racing as she tried to fit the pieces together. Unpaid bills, her child, complex family dynamics, a boyfriend in prison, her workload and dealing with the side-effects of the protease inhibitors all preoccupied her and surfaced repeatedly during our first conversation about hope.

There are *worse* things than HIV

I can see clearly now, the rain has gone,
I can see all obsacles in my way;
Gone are the dark clouds that hold me down,
It's gonna be a bright, bright, bright, sun-shiny day!

("I Can See Clearly Now" Holly Cole, 1998)

In between our first and second conversation Grace was involved in a serious automobile accident. Her vehicle was demolished and Grace was first airlifted to a shock trauma unit and then underwent six weeks of recuperation and therapy. Additionally, while in the trauma unit of the hospital, Grace had stopped breathing. As the nurses scrambled to deal with the code blue, Grace described having an out-of-body experience during which she saw what was happening around her but she was away from her body, looking down at the frenzied scene. She also described feeling an overwhelming sense of calm.

When I met with Grace the second time, she had been home from hospital for just a short while. She was in a tremendous amount of pain from her injuries and had difficulty getting in and out of her chair. As she was still quite frail, her daughter continued to stay with Grace's parents, where she had been since the day of the accident. During that second conversation there was a noticeable difference in the way Grace talked about her experience of hope. As she realized its seriousness, the accident had a sobering effect on Grace. There was a calmness about her that had not been present just a few months earlier. Still as vivacious and eager as the first time we met, during this conversation however, Grace was more focused. She was clearer about her experience of hope and determined to communicate it with me. In particular, Grace wished to convey two things: first, her absolute conviction that she was not going to die as a result of the accident and, secondly, her change in attitude resulting from the realization that death could come at any moment:

> *...And now I feel better about the HIV because I know that we can die any day. And HIV is nothing compared to the challenges out there. There are more things that could be*

worse than HIV. I could have died... I could have been paralyzed... I could have lost my legs... I might not be able to move my hand... and I was just thankful all along that I was alive. I mean, think about it, I could have died! I could have been gone, like, dead, you know? Now I have a different outlook. I just need to make the best of every single day because it [death] can happen anytime...

This change in perspective was important to Grace's experience of hope. Because of the terminal realities of AIDS, HIV is a confrontation with death. But the immediacy of death which Grace experienced as a result of the accident dramatically changed her perspective about life and HIV/AIDS. This change in perspective was part of Grace's experience of hope:

... Before the accident I used to say, you know, 'I don't want to die of HIV, I'd rather die in a car accident or something... I've changed my mind... (now I want to die of a heart attack) [laughter]... but there were times before when I just, you know, would pray and think that please, I want to be with my child until she's five. And now I know that, hey, there're people out there with HIV who've been here for fifteen years...

An Inner Knowing

Grace's accident was itself life-threatening. She could have been killed immediately when the other vehicle collided with hers. She could have died later as a result of her injuries. Grace did not die, but a few days after the accident, she went into physical distress. Grace stopped breathing. Still under intensive care, the professionals rushed to save her. Grace knew that all of this was happening; in fact, she watched everyone from above, as if she was not a part of her body during those minutes:

... Two days after coming to the hospital I stopped breathing... I literally died. I saw the doctors and nurses and heard them and all... and at that time I was just very peaceful [feeling that if] I died that day I would have been fine. Like it wouldn't have been that big of a deal, you know? 'Cause I wasn't like, terrified or scared to die... I was just, very... calm. That was an experience of hope, because after that I felt different... like, I know everything is going to be OK... I know I am going to get better... as long as the Lord is on my side, I can beat anything...

Previously she had feared death; but rather than feeling panic at the moment of death, Grace experienced a sense of calm. She said that felt the presence of God. Along with the sense of calm was a deep awareness that *"everything was going to be OK."* She felt/knew two things, that she had nothing to fear from death, and, secondly, that the sense of calm was unlike anything

she had ever felt before; she felt fully at peace. For Grace, that incident in the hospital was an experience of hope.

As Grace describes this experience she repeatedly uses variations on the word "know" to describe what takes place within her: *"I just knew everything would be OK"; "I know I am going to get better"; "I know that [God] is with me."* Grace's experience of hope is characterized by an inner knowing – it is purely subjective. She might have said it was received from outside of her: the gift of God's presence and resulting sense of peace, and yet the knowing is not external to her. Grace describes 'knowing' that she will get better and knowing that she is able to beat anything. Grace said, *"As long as the Lord is on my side, I can beat anything."*

Upon review, it is unclear whether by 'beating anything' Grace is referring to HIV/AIDS, or to the near-death experience and aftermath of the accident. I find the juxtaposition of circumstances and lack of clarity significant in conveying the essence of her experience; as if the two circumstances are one and the same. Grace beat-the-odds against her: walking when she was told she might never walk again and recuperating far beyond the expectations of the experts. Grace 'knew' that she would recuperate from the injuries she sustained in the accident. And she did. Later she 'knew' she could 'beat anything' (including HIV), despite the odds and opinions of the experts.

There is another area in which Grace's words are unclear and yet revealing. In the following excerpt we hear Grace talk about beating the virus, and continuing to heal from her injuries. At the same time, Grace conveys an acceptance of the fact that death can come at any time:

> *...Now I know I can beat this [these injuries] and I can beat the HIV too, I'm gonna live a long time and when it's my turn to die, I'm gonna die. And it doesn't matter if it's HIV, if it's a car accident, it's a heart attack, cancer, whatever... when it's our turn to die it's our turn... you know...*

Grace is a deeply religious Christian who lives with a life-threatening illness that holds little prospect for a cure. This, coupled with her accident and near-death experience has caused

her to experience hope in an extreme and unique circumstance. Her experience of hope is caught up in the peacefulness she now feels and 'knows'. The inner-knowing allows her to live with a sense of trust, which, in turn, provides her with peace. All of these contribute to Grace's experience of hope:

> *...I'm not hopeful I'm more, trusting in... in that God will take care of me and take care of us and, you know, things are kind of meant to be the way they are and I just need to do all the things that I can do in my power to keep healthy and to provide for my daughter as long as I can...*

Grace's Photos

Grace responded enthusiastically to the photography portion of the project. I gave the camera to her after our first conversation, but she didn't take any photos until after her accident. The injuries sustained in the accident hindered Grace's mobility; consequently, most of Grace's pictures were taken in and around her home. The first picture Grace showed to me was one taken of her daughter, "*...because she's a lot of my inspiration; I live to know that I need to teach her...* " Two or three other pictures of her daughter were included:

> *... This is of course our snowy day. I took pictures of my daughter playing in the snow 'cause that's always exciting and so is, just, the snow. A picture of the snow and day in the back and when it freeze... and here is another of my [daughter] once again smiling away. And it's snowing actually if you can see... and of course here's my [daughter] again with her slippers... she's just been a blessing in my life. She's my little hope and inspiration...*

One picture was taken of a wall hanging on which was printed the saying: "Life Is like a piano, what you get out of it depends on how you play it." The next photo came with this comment, "*... And of course hope is my bed; knowing that there, you know, like, you can go and lay down and go to sleep and get a fresh start. I love my bed, I love to go to sleep...* " Two other photos included items that connected Grace to her grandmother:

> *... This is a picture of a hymnal. It was my grandmother's hymnal. And there's two hymns that I love. One is, 'What a Friend We Have in Jesus' so I took a picture of that song... Then I have this picture. This one is really neat because it has a lot of meaning to me. This is my grandmother's Bible passed down to her. She's no longer alive. And this was her pillow and this was her blanket she crocheted. So I put them all together in this picture. It was funny, actually, that the blanket was on the chair and so was the pillow*

when I was in the car accident and so I thought of this often in the hospital. So I put the Bible there and took a picture of that because my grandmother was a very very religious lady and she just brings me hope thinking of her. She lived until she was ninety some years old and she was full of life. She was definitely full of life all her life...

Had she been able, Grace would have gone to various places to photograph her experience of hope: "*...I would have taken photographs of nature and the outdoors because that gives me a lot of peace.*" Instead, because of her physical limitations, Grace took her time and thought hard about the content of her photos:

...I thought about the photographs a lot... at first I looked around the house trying to figure out what things I could take to show my hope. And I went to bed at night and I thought about what things I could take when I was feeling hopeful. There were a couple of things that I thought of and one of them was the flowers and making sure I get the picture of the Bible... and the angel, because I know I have lots of angels around me...

There were indeed photos of the Bible and the angel to which Grace had referred but no flowers, so I asked Grace what she meant. She told me that, because it was winter, she wasn't able to take the photo she envisioned; otherwise she would have included a photo of flowers for the following reasons:

...I don't know. It's so hard to explain. It's just there, you know? It's just that feeling of hope. Feeling of things continuing, going on, and growing. The flowers represent hope by just that they are here, they grow. ...they're God's creation just like we're God's creation. They mature and grow and they die when it's their turn to die, just like us; just like humans. And the trees, you know? They continue to live for years and years and years, and I think that's a neat symbol. That's hope.

As Grace described her pictures, there were two which she claimed to be "odd":

...This might be a very odd one but I have a picture of my medicine cabinet with all of my medications. That's something that gives you a lot of hope because you know how they are coming up with lots of good medications these days and vitamins and stuff like that. I took a picture of that because that's very hopeful knowing that they may come up with a medicine that will eliminate HIV, maybe, you, know, completely so that's something that we should definitely think of as very hopeful... and this might be a little odd. I took a picture of my phone because one of the things that can give me hope is just talking to other people. And, that makes you feel better, you know? When you feel low, or things are going down, when you talk to somebody else, maybe in support group or somebody else who's going through the same thing... it's very helpful, you know? You can get a lot of hope from other people...

There were two other pictures Grace talked about. One was a picture she wished she could capture and the other was an actual photo, not taken as part of this project, but relevant nonetheless. Just a few days before we met to discuss the photographs, Grace's father had taken her to see the demolished vehicle she had been driving before the accident. Evidently, the car had been totaled and the mechanics found it hard to believe that anyone could have survived. Grace was overcome by the sight and the fact that her daughter would have been killed had she been traveling with Grace that day:

> *...um, there was practically nothing left of the car...just one seat where I was. The side that was hit was all smashed in and that's where my daughter would have been. If she had been in the car...she wouldn't be here...her car seat was tore up and ripped into several, several pieces. When I saw that car I said to myself, 'no more complaining or whining about little back aches and this hurts, that hurts, because I should be thankful I am here.*

While looking at the car, one of the mechanics came to Grace and handed her an envelope saying, "Here, I found this in the car and thought you might want it." When she opened the envelope there was a crumpled picture of Grace and her daughter. Grace was deeply moved by this saying to me, *"That picture of the two of us survived that terrible accident! I thought that was pretty neat. Out of all that rubbish, you know, he found a picture of me and my daughter."* Grace felt that story to be a profound message of hope. The other picture mentioned by Grace was one she never took, but described for me:

> *...If I could have taken a picture of this I would have, and that is, when the sun shines in through my kitchen window in the morning when it's bright and sunny. I don't know, but it is hope...just, like, it kind of gives you hope that there's a new day and that there's the end of the day every day and that life goes on. On and on and on...*

A Snapshot of Hope: Grace

Carol was here yesterday and left this camera for me. She wants me to take pictures when I experience hope. Well, what if I am hopeful all the time, what then? I just feel so glad to be alive that each day is like a time of hope for me. I am so thankful that the Lord has been so good to me. I mean, here I am back home just six weeks after a car accident that could have killed me. The Doctors didn't think I'd be able to walk again or use my arm and just look at what I can do! Sure, it's slow going. I hobble a bit and I am in a lot of pain, but at least I'm in my own home and can

sleep in my own bed! Soon, I won't even have to use this cane, and my daughter can stay here with me again. When I think about that car accident, and all I've been through since then, all I can say is, there are so many things that could be worse than HIV. I could have died! I could be dead. HIV is nothing compared to that!

I've written in the journal Carol gave me and now I want to take some pictures. I feel so good today, so thankful to be here, and it is so nice to be home. I am sure that the Lord is with me and that there is some reason that I am still alive. I never once felt that I was going to die, even in the hospital when I stopped breathing. I just felt peace... overwhelming peace... and I just knew God was with me and that everything would be all right.

I just can't worry about things anymore, that's for sure! I am looking at everything differently, I'm just so thankful for being alive, and so sure that when my time comes, that's my time and there's nothing I can do about it. It just feels so good knowing that.

I can sit here in my chair and see the sunbeams coming through my kitchen window onto my plants. When I look at that I just feel so thankful to be alive! It's a new day!

A Representation of Grace's Experience of Hope

The Figure representing Grace's experience of hope depicts the sun situated within the body of the person. Grace's experience of hope was tied together with her experience of a sense of peace and an inner *knowing*. Thus, there is just the solitary person; the light comes from within, and generates outward.

Figure E: A Representation of Grace's Experience of Hope

The Unique Experiences of Hope

The following figure presents a representation of the unique themes of hope as explored in this chapter. Situated in relation to the word hope, the themes are placed with each participant's name.

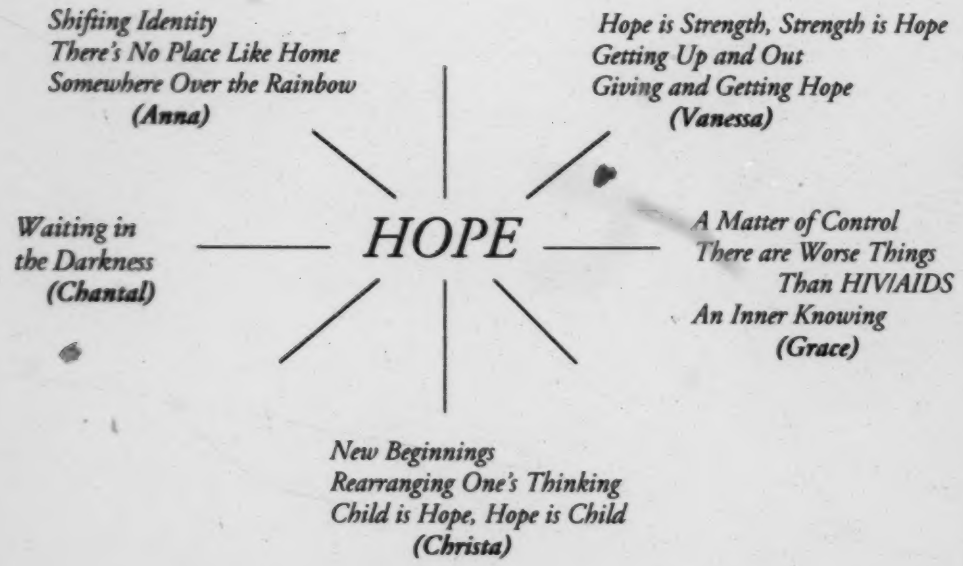


Figure F: A Representation of The Unique Themes of Hope

CHAPTER SIX

THE EXPERIENCE OF HOPE

As demonstrated in Chapter Five, Chantal, Anna, Grace, Christa and Vanessa each experienced hope uniquely. Concurrently, within the unique descriptions we hear hope experienced as a combination of dynamics. Some are active, such as *'giving and getting hope,' 'rearranging one's thinking'* and *'getting up and out'* of a place of hopelessness; while others are more subdued (*'an inner knowing'*; and *'hope is strength'*). Additionally, hope is experienced within (and as a consequence of) each woman's life context.

The hermeneutic quest is to discern from within the unique strains the connecting melodies that create harmony. The hermeneutic imperative calls for exploration, to move beyond personal meaning toward a place of mutual understanding. It necessitates a searching in order to unearth those dynamics at the core of the experience. For example, does Anna's 'yearning hope' resonate with other people's experiences of hope or is this particular only to Anna? Likewise, is hope *the same as* 'moving up and out' of a deep darkness, as Vanessa experiences it? Does that particular description lead to a more profound understanding of hope—uncovering something fundamental, more generally meaningful about hope? Or, does that description remain uniquely Vanessa's experience? These are the questions of hermeneutics, those that won't allow an exploration to end with description alone, but which seek a deeper, more collective understanding of the phenomenon.

Phenomenological text flourishes on a certain irrevocable tension between what is unique and what is shared, between particular and transcendent meaning, and between the reflective and the prereflective spheres of the lifeworld (van Manen, 1994). We move now toward the place where difference and sameness interplay and meaning begins to take shape. Gadamer's (1989) descriptive phrase "a fusion of horizons" aptly describes the process leading to the formation of

meaning. At some point, individual, divergent perspectives (fields of vision) merge together in mutual understanding. This is the process of meaning-making.

The following diagram portrays the figures depicted in Chapter Five. In this diagram the figures are together: oriented to the word hope and encircling it. Because sunlight was integral to each woman's description of her experience of hope (including Chantal from whose experience the sun was notably absent), each *individual* woman's experience is again depicted using the sun. Additionally, there are rays connecting each of the figures to the word HOPE. Instead of remaining as disconnected, separate experiences, in this diagram each figure is now brought together, creating a holistic representation of the experience of hope.

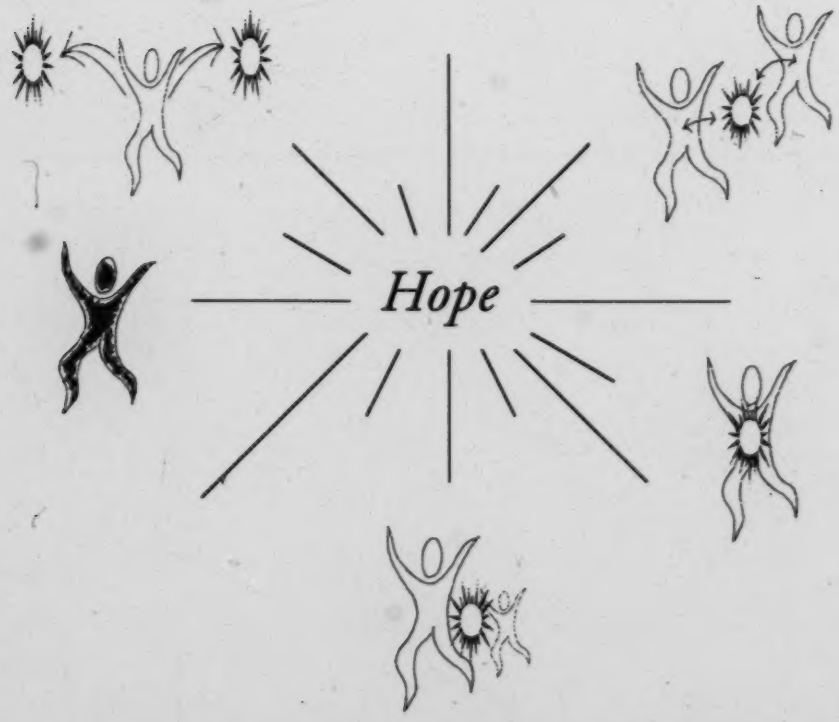


Figure G: A Representation of the Experiences of Hope

With the exception of Chantal with whom I met only once, all of the participants mentioned sunlight as an image of hope; some even attempted to photograph images of sunlight to represent their experiences of hope. Christa saw hope in *"a beam of sunlight on snow-covered trees."* Anna pictured hope *as "the sun glistening on mountaintops."* Grace pictured hope in the *"sunlight coming [through my] kitchen window shining on my plants,"* while Vanessa pronounced defiantly, *"the sunrise [shows me] that I got through another day... and that's hope!"* That the image of light was central (and linked with hope) was emphasized as the women discussed their experiences of hopelessness, which was linked with darkness.

Along with the experience of hopelessness, and the image of sunlight, other common threads were discovered within the women's experiences of hope. These threads include the following: an action component; experiencing hope as both an inner and outer reality; experiencing hope as a present inner knowing; and experiencing hope as possibility. Each of these threads was woven through the individual descriptions of the experiences of hope. Together these threads create the warp and weft of a larger tapestry, namely, the experience of hope. Because of the centrality of light as an overarching symbol of hope, I have named these five threads using the metaphor of light:

- Hope: In the Company of Hopelessness
- Hope: An Inner-Outer Light
- Hope: The Impossible Possibility of Light
- Hope: Moving Toward the Light
- Hope: A Present Light

The following diagram portrays the common threads, oriented around the center word, "Hope". A hermeneutic phenomenological exploration of each theme follows.

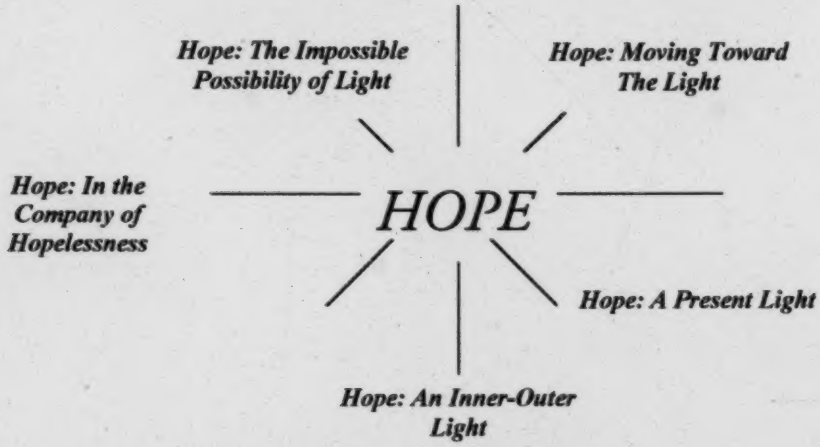

Hope: The Impossible Possibility of Light
Hope: Moving Toward The Light
Hope: In the Company of Hopelessness
HOPE
Hope: A Present Light
Hope: An Inner-Outer Light

Figure H: A Representation of the Common Threads of Hope

An Interpretive Exploration of the Common Threads of Hope

Hope: In the Company of Hopelessness

I arrived at [Chantal's] apartment just before noon. The sun was shining – at its peak – as I waited for Chantal to answer the door. I looked around, reflecting on what a perfectly clear, glorious day it was. The sky could not have been bluer and the crisp February air made everything even more brilliant.

Chantal timidly greeted me at the door. As we ascended the steps to the second floor and entered her apartment, for a moment, blindness struck as my eyes adjusted to the abrupt change. Chantal's living room was completely dark! The shades were drawn over both windows, and there was no artificial light to cut through the gloom. A slight glow came from the flickering blue of the television screen and traces of daylight seeped in around the edges of the shades. Chantal made no attempt to bring light into the room, either as I arrived or while I was there.

The thick darkness was disconcerting to me and I was aware of the incongruity between sitting there in the dark and talking about hope. It felt as if there was no hope in the room, and I desperately wanted hope to be present. I tried a number of times to prompt Chantal to reflect upon (even)

past experiences of hope, but the air was thick with hopelessness. Chantal told me that she was too tired to think about hope and that was evident.

It was such an effort for her to talk to me. She was open about her problems and worries, but just couldn't recollect an experience of hope. The weight of her problems was almost too much for her and she appeared to be barely hanging on.

As I sit here, I can't even recall the colours or the furniture, walls or carpeting as my entire recollection is of both the heaviness of our ensuing conversation, and the heaviness of the surrounding darkness...the two seemed so intertwined. Chantal spoke briefly about hope, but her words, her current situation, and her affect conveyed only a sense of hopelessness.

I was uncomfortable and became worried for her, feeling some need to help her, just as I felt the need (and had to fight the impulse) to go over and fling open the shades - to let some "light" into the room.

(From Carol's Journal)

Darkness has long been a metaphor for hopelessness and fear. Artists have used 'the dark' and shadings of light and dark to convey a sense of doom, to engender terror, or to bring to consciousness deep feelings of the unknown. The lights go dim in a theatre and our eyes naturally widen with expectation, our hearts quicken. We are vulnerable to that which is to come. A familiar path during the daylight hours becomes sinister when darkness falls. In much the same way our day-to-day living is a familiar path, becoming sinister and unfamiliar when faced with a crisis of body or spirit. Times of grief, the time of a life-threatening diagnosis or times of struggle may make the familiar seem dark indeed.

Philosopher Gabriel Marcel (1978) describes hopelessness using the metaphor of darkness. Hopelessness is the darkness arising from situations of extreme personal turmoil. Marcel (1978) makes the claim that we must take seriously "the darkness": the darkness that comes from some time of trial, illness, separation, exile or slavery, a darkness wherein "...[a person] is deprived of a certain light for which [one] longs" (Marcel, 1978, p. 30).

> . . .for now the thought
> Both of lost happiness and lasting pain
> Torments him. . .
> At once, as far as Angel's ken, he view
> The dismal situation waste and wild;

A dungeon horrible, on all sides round,
As one great furnace flamed; yet from those
Flames

No light, but rather darkness visible
Served only to discover sights of woe,
Regions of sorrow, doleful shades, where
Peace
And rest can never dwell, hope never comes. . .

(Milton, 2000)

Darkness and hopelessness become one and the same in the excerpt from Milton's epic Poem, *Paradise Lost*. The fallen angel's arrival in hell suggests that there may be a *place* of hopelessness, a place of darkness.

The women involved in this study also experienced hopelessness as a place. Christa remembered Germany as a place of hopelessness; Chantal's apartment felt like a place of darkness/hopelessness; Anna locked herself in her room and Grace was away from 'home' in a different physical place, when experiencing hopelessness.

> *... [When I first learned I had AIDS] I guess you could say I shut down, that's the first thing I did, shut down... every time my family left me in the room by myself I broke down and cried... I felt hopeless, like, what was I gonna do? I just thought despair, death. I felt like I was the only person in the world that was goin' through this... I didn't have any energy... no desire to do nothin'. I didn't want to see nobody; I didn't want to talk to nobody. I just wanted to be left alone, to sit in that darkness...*
>
> *(Vanessa)*

> *... When I was drinking and doing everything else, that was probably when I felt hopelessness. That was before [child]. I didn't care about anything or anyone. They were dark times...*
>
> *(Christa)*

> *... I feel hopeless now because I need a job (welfare turned me down for cash assistance) and I'm getting no child support. I feel hopeless, what am I going to do? I have no hope. Everything is just such a burden...*
>
> *(Chantal)*

> *... The day my Dad passed away I was hopeless... it felt as if there was nothing I could do... It was a horrid feeling... just like the day I was diagnosed; those were my two hopeless times... I locked myself up, I just sat home by myself and did nothing... and*

thought about suicide...

(Anna)

...I was very hopeless in the beginning thinking, you know, that I'm not going to make it. I'm not going to be around very long. . .I always thought I'd commit suicide if I ever got HIV. . .I can't believe how depressed I was when I was at the shore after finding out...I remember walking along the ocean, and just, just crying and crying...

(Grace)

Vanessa likened hopelessness to being enclosed in a box, having no way out:

... Whatever happened to me before, I was always able to get out. This time, there was no way out. No matter where I turned, it was like a square or circle [she puts her hands out in front of her and mimes being trapped inside of a box] and I'm in the middle and I can't get out... there was just no way out... and I stayed in that place for six, seven months...

What is hopelessness? The Seventh Conference on the Classification of Nursing Diagnoses includes "hopelessness" as a diagnosis. Hopelessness is defined as "the subjective state in which an individual sees limited or no alternatives or choices available and is unable to mobilize energy on his or her own behalf" (O'Toole, 1997, p. 754). This definition has at its core, human agency: an individual "sees" no choice and is unable to mobilize energy towards personal gain. "Seeing choices" appears antithetical to the experience of hopelessness as described by the women of this study for whom hopelessness is a felt rather than a cognitive experience. Interestingly, the word hope is not included in the Miller-Keane dictionary. Still, one wonders about its relationship to hopelessness as defined above. Is hope among the (many) choices available, but one which the individual may not "see"? It is difficult to see in the darkness; perhaps one cannot see hope because of the overwhelming sense of darkness/hopelessness.

Thomas Merton, a Christian mystic describes hopelessness using the stark images of a desert: "I have been summoned to explore a desert area of [the human] heart in which explanations no longer suffice... An arid rocky dark land of the soul"(1969, p. 90).

Merton's desert imagery invokes images of a stark place, a place of isolation and barrenness. Accentuating the imagery, Merton (1969) further describes hopelessness as "[an] arid

rocky dark land of the soul" a 'place' without hope. Clearly, hopelessness is a place one doesn't want to be; it is not a comfortable place.

Each of the five women experienced hopelessness as they faced death: either their own when confronted with AIDS, or the death of loved ones. Their *descriptions* of hopelessness, however, had little to do with physical suffering. Instead, hopelessness was described as a sense of emptiness, a time of numbness, and the feeling that nothing mattered. *"[When I was hopeless], I didn't give a shit about nothin... I was just, like, 'whatever"; "I didn't want to see anybody or talk to anybody"; "Hopelessness is like, what's the use?"; "I was just like, what's the use? I'm telling you nothing mattered!"* Hopelessness was first experienced as an emptying out, a loss of concern for others, a loss of control and loss of a sense of a future.

Underlying the emptiness of hopelessness was a sense of isolation. Grace and Vanessa used similar words saying, *"At first I felt like I was the only person in the world."* While Anna said, *"It just feels like you're alone, empty inside."* And Chantal asked, *"Who was I supposed to talk to? Who?"* Compounding the isolation was the tendency to keep their diagnosis to themselves, with each disclosing her HIV status only to a select few individuals, for fear of rejection. The loss of emotions and emptiness of feeling caused four of the women to contemplate suicide, and one participant attempted to have an abortion. For another, hopelessness was best described as the period of her life when addictions insulated her from her emotions. Hopelessness then, is emptiness. Like death itself, hopelessness is an end to care, motivation, and the spark of life.

"I felt hopeless, it was like despair, death... "

"I just can't believe how hopeless I was... in a state of despair"

The words hopeless and despair were used interchangeably by the participants. Interestingly, etymologically the two words are more alike than different. The word despair comes to English via Latin and Old French. The addition of the preposition *de* or *des* (meaning

'down from', 'away from', 'off' or 'aside') to another word negates, or reverses of the word's definition. In this case, the root word *sperare* (or the more modern equivalent espoire) is the French word for 'hope'. Therefore *de* + *espoire* creates the reversal: one is away from or cast aside from hope (Hoad, 1986). The English word *hopeless* attempts to portray the same meaning as the French: one is without hope.

For Ellul, (1977), there is a clear distinction between the two realities despair and hope. The loss of hope is unmistakably more tragic:

> ...Despair is aware of itself. It cries out. It is tragic and romantic. It gives rise to acts of heroism and to 'beautiful song.' It drives [a person] into action. It incites to rebellion, and challenges the person to be more truly [a] self. The end of hope, on the other hand, is discrete and silent...It gives rise to nothing...one fades away because, where there is no longer is any hope neither is there any form of being (1977, p. 70).

The construction of the word hopeless implies the absence of hope: one is without hope, hope-*less*. Logically, it appears that in order to feel the *absence* of something we must first know or understand that thing's *presence* (hope). Yet hope*lessness* itself may well be a *presence* rather than (merely) the *absence* of hope.

Many emotional dynamics are triggered with a diagnosis of HIV. The initial experience of hopelessness may feel like an 'empty place'. Very quickly however, that 'place' is filled with emotions including fear, anger, shame, and self-doubt. *" I felt a lot of things: shame... anger... loneliness." "...I felt dirty." "I felt disgusted. . .and afraid."* There can be feelings of anger towards and betrayal by others such as past lovers: *"I am angry at the guy... I don't think I hate the person who did this to me, I'm just angry that if he knew and didn't tell me."* Or, there may be anger directed toward oneself:

> *... [At first] I was angry that I got tested... [and then I thought] why didn't I get this before? I was promiscuous in high school and college and I should have gotten it then, not now, you know? I got faith when I was pregnant with my daughter and I was like, this*

is the time when I shouldn't have gotten it, you know? I'm pretty much doing good right now.

(Grace)

...My daughter said to me, 'How could you believe in a God that lets this happen to you?' I tried to explain to her that it's not God, it's sin that brought this on, it's somethin' I did.

(Vanessa)

...After my diagnosis, I didn't like myself, I hated myself at the time...

(Anna)

Compounding these emotions is the sense of shame associated with HIV:

...I was so disgusted with myself, I was ashamed... if someone would just touch me like this with their arm I would say, 'don't touch me' ...all because I have this virus...

(Chantal)

...I felt dirty, cheap... It was just, just a horrid feeling.

(Anna)

...I felt shame, shame... a whole lot of shame...

(Vanessa)

When in the presence of another person we say we are in that person's 'company'. What does it mean to be 'in the company' of hopelessness? This is not a comfortable companion who travels lightly. Quite the contrary, hopelessness brings along a certain amount of baggage, including in this case the beliefs, assumptions, and prejudice associated with HIV/AIDS:

...I don't even know if I should say this 'cause this sounds very prejudiced myself, very bad. But I was thinking like, you know, I'm not a druggie and I'm not a gay and, and it shouldn't happen to me...

(Grace)

...but you sit and listen to people who don't know [that I am HIV positive] and you hear how they feel about HIV and AIDS, you know? Like, you hear comments about people being whores or drug addicts and, you know there's part of me that just wants to scream and say, 'Is that how you feel about me? Because, guess what? That's what I am...

(Anna)

Self doubt, guilt or personal culpability crowd the place of hopelessness and become companions too within that space. With HIV comes the additional chastizement from others who believe those infected with HIV have 'gotten what they deserve' through illicit behaviours. Some of these messages can become internalized:

... [When he said those nasty things] I kind of felt, like, well, that's true. I shouldn't have done it 'cause after my daughter was born I was going to wait until I was married to have sex again... so this was a consequence of my actions. I didn't think of it as a punishment, but as a consequence of my choices...

(Grace)

... before there was always a way out, but not this time. You say to yourself, 'There, this time you really did it'... It, it's hopeless!

(Vanessa)

To talk about these emotional challenges as companions may appear absurd. How could self-doubt, anger and shame—realities with obvious negative implications be named as 'companions' when companionship implies something softer, friendlier, and more positive? The feelings of guilt, anger, shame and fear surface and resurface as the women move through their days. Thus, the emotions connected with hopelessness are ever-present, 'companions' with which each woman must become compatible in her own journey. These emotions fill the place of hopelessness making it more crowded than empty. Even Merton's (1969) desert place of hopelessness is not empty; rather, "...[It] is sometimes illuminated by strange fires which [we] fear and peopled by spectres which [we] studiously avoid except in [our] nightmares" (p. 90).

Although she has 'been there', hopelessness is not a place in which Vanessa stays. Neither does Grace stay in a place of hopelessness. Anna's memories of hopelessness are vivid and she acknowledges the difficulty of moving from that place: *"How do you tell someone life goes on, it gets better, cause it doesn't seem to as far as I can see... you try and you try and you can't get anywhere."* Christa is far from the place of addiction and hopelessness experienced in her past and tries not to remember her years in that place.

Nevertheless, hopelessness is never far away; it is a place to which one can easily return:

... Some mornings I just wake up and feel like, what's the use?

... I tell you I can feel really good sometimes and all of a sudden I'm right back there [in a place of hopelessness].

... Sometimes I have to fight to keep from going back to that hopeless space...

... I still think about suicide at times, it's just like, always there, you know?

If hopelessness is a place to which one can return, it can also be a place *from which* one can leave. Marcel (1978) contends that it is *only* from within a situation of hopelessness/darkness that one truly experiences hope: "...it is impossible to separate 'I hope' from a certain situation of which it is really a part, situated within the framework of the trial" (Marcel, p. 30). If this is true, then hoping can (only) occur when one feels pushed to an emotional or physical limit through crisis or illness or personal tragedy: the place of darkness/hopelessness can become a departure point for a journey towards hope.

> "It's a long walk in the dark
> on the blind side of the moon
> and it's a long day without water
> when the river's gone
> and it's hard listening to no voice
> when you're all alone
>
> So take a hundred lighted candles with you
> when you walk on the moon
> and quickly tie a knot in the river
> before the water's gone
> and listen for my voice, if for no other
> when you're all alone"
>
> (Aiken, 2000)

If the first stanza describes what hopelessness is like, and if there were no end to the darkness, then the poem would simply end with stanza one, leaving the reader to feel the lack of direction and solitude of this "long walk in the dark." There would be no movement, no change. The poem however, does not stop within the isolation and darkness of hopelessness. Incorporating the contrasting images of light and dark, the poem offers a glimmer of hope, a movement from the dark place of hopelessness.

Vanessa, Christa, Grace, Anna, and Chantal knew the darkness of hopelessness. Nevertheless, while in the company of hopelessness there were experiences of light/hope.

> *...It's like I said to someone the other day. 'One day you'll stop cryin'... It's OK... go ahead and cry; feel that pain. Don't hide it, you know'... I said, 'One day the tears are*

gonna dry up and you're gonna wake up laughin and you'll be like, damn, a whole day went by and I'm not cryin' no more!'

Hope: An Inner-Outer Light

...Hope has to come from within... you know? You're sitting in a bed and can't move for two weeks... and if I didn't have the help or the spirit or the positive attitude to say 'I can do this', if I didn't have the strength... knowing that the Lord's going to take care of me, I don't know where I'd be.

(Grace)

When first asked about hope, Vanessa replied, *"I get my strength from God."* Chantal spoke of wanting to be strong for her children; Christa spoke of a desire to achieve goals and, Anna experienced hope within her memories and recollections of the past, a deeply felt internal experience. What does it mean to say that hope comes from within? Is hope a part of one's physical nature, a characteristic of one's being? If it didn't come from within, would it be hope?

The word hope is often used interchangeably with words like 'strength' and 'faith'. The word strength commonly refers to a physical attribute: one is 'strong' and has the power to withstand or resist great force. Likewise, the word strength can also be used in reference to one's character or disposition. Both Grace and Vanessa's use of the word encapsulates these dual meanings. Situated within, strength/hope provides the impulse and power to respond to life's difficulties.

The etymology of the word 'strong' follows its roots through Old English to the Germanic strang, the root of the word string, or that which binds or holds together (Hoad, 1986). Hope/strength holds us—keeping us together during times of great need. Moreover that which holds us together may be both internal and external to us. Chantal seemed to be *hangin by a thread*, bound to some memory of hope and hanging on to her social worker in the attempt to experience hope again.

How does hope come about 'inside' a person? What makes hope happen? Victor Frankl's (1959) moving account of life in a Nazi concentration camp is a testament to the experience of hope in the midst of incredible misery, where people literally were "stripped of everything except

their own naked existence" (p. In these inhuman conditions, in the midst of unimaginable human suffering many found meaning and hope, including Frankl himself.

"To Hope"

When by my solitary hearth I sit,
And hateful thoughts enwrap my soul in gloom;
When no fair dreams before my "minds eye" flit,
And the bare heath of life presents no bloom;
Sweet Hope, ethereal balm upon me shed,
And wave thy silver pinions o'er my head.

(Keats, 1884)

This poem depicts hope as something *outside* of oneself – a separate entity that may even answer or appear at the pleading of a desperate person. If hope is outside of oneself, how do we 'get' hope? Engaging in prayer, attending church, talking to a friend, listening to tapes are some ways the women of this study get hope from outside. Similarly, hope can be initiated through an inspirational poem, a picture, or an image: *"When I see a candle sometimes, that light in the darkness, it just gives me hope". "People showed me scripture; they gave me healin' tapes and cards, and that helped". "I don't know what I'd do without prayer."* In particular other people become sources of hope: friends, children, family members, health care professionals and others can give, inspire or initiate hope and are therefore integral to the experience: *"Whenever I'm down I just call up my friend." "When I come out of the Dr.'s office and I have a bad day, I go see my friend to cheer me up, give me a hug and that's it; she just helps keep me going."* These initiators of hope, clearly coming from outside serve to spark an internal sense of hope. At least part of the experience of hope then, comes as a result of some outward prodding. *At the same time*, hope is experienced as an inner response to something heard, seen, read or given:

> *...I don't really know what the difference between faith and hope is: I'll have to get a dictionary to figure it out. But I do know this I know that Jesus and God and angels and my spirit guide are helping us out. I wouldn't have gotten this far on my own. Somebody has to be helping me; but hope and faith go together in that way...*
>
> *(Grace)*

Grace cannot distinguish between her (Christian) faith and hope because they are so intimately bound. Concurrent with her internally felt hope/faith is the presence of God and Jesus outside of herself as one who will take care of her and her daughter: "*I guess I use more like, you know, hope more as faith than hope. I'm not hopeful, I'm more, you know, trusting in the fact that God will take care of me and us*".

Victor Frankl's (1959) account of hope experienced in the midst of a Nazi concentration camp reflects the dialectical relationship between the internal and external in the experience of hope. Even though he had no way of knowing whether his beloved wife was still alive, Frankl's deep connection with her, the ability "still to be carried away by nature's beauty" (p. 59), and his affirmative "yes" to the question of an ultimate purpose (p. 60) indicate that the experience of hope is both inside and outside of a person.

Photograph 1: "A New Beginning" by Maxine Noel[1]

[1] Verbal permission to use this reproduction was granted by the artist in March 2001 with the proviso that no profit would be made by its use.

Maxine Noel's (1999) painting "A New Beginning" depicts a mother and child. In the painting, the child's figure is incorporated into the mother's, making it difficult to discern where one figure begins and the other ends. The Inner-Outer experience of hope is well-represented by this image: there is a melding of the two.

Because it is so particular to women's experience, 'pregnancy' can become a profound metaphor to convey the *Inner-Outer* experience of Hope. During pregnancy, the child is enveloped within the mother –they are two separate entities yet wholly interrelated. Hope is often experienced in relation to a child, and in varying ways, each of the women related hope to children. Because it so clearly marked a turning point for her, Christa's pregnancy became emblematic for her as a time of hope. Chantal mentioned her first pregnancy as a time when she remembered feeling hope. At least part of Anna's melancholy was rooted in the loss of potential pregnancy due to HIV. Grace found hope in the possibility that she might someday have another child; while Vanessa said, *"My children keep me going"*. Perhaps hope is like a birthing experience of sorts, felt and known intimately within one's body and yet remaining wholly separate, at times even held and nurtured by another.

Hope: The 'Impossible Possibility' of Light

> *"When I hear that word hope I guess I do think 'cure', that one day there will be a cure or one day there'll be a vaccination to stop the spread of HIV."*
>
> *(Vanessa)*

In the movie Oh God (1977) an otherwise unremarkable grocery store manager (played by a young John Denver) claims to have seen, talked to and been in the presence of God. As the movie progresses, the viewers are part of the action, observing precisely that which the grocery store manager must prove to others: that God has visited him in the form of a sweet old man (played by the actor George Burns). As viewers, we are also witnesses: seeing the interactions between "God" and the grocery store manager; seeing God appear and disappear; seeing God perform minor miracles and seeing God address such profound issues as life, religion and God's

very existence. As witnesses, we are carried along, believing/knowing that George burns is indeed "God". We know that the grocery store manager is telling the truth but watch him get ridiculed by the media, his co-workers and (even) his family because of his drive to convince others about the truth of this preposterous idea. Religious leaders are in an uproar; the grocery store manager is accused of blasphemy and is eventually brought to trial for continuing to insist that he has seen God.

The climax of the movie pivots around a dramatic courtroom scene. The grocery store manager has chosen to defend himself rather than being represented by a lawyer. As he stands and faces the judge, he buttons his coat and says, "I call to the witness stand one witness, and one witness only: I call upon the Lord God." There is a hush in the courtroom. Dead silence hovers for a moment. Slowly the silence gives way to soft whispers. Soon the murmuring begins followed by giggles and outright laughter. The noise in the courtroom continues to increase as the spectators recognize that they have been fooled. God has not shown up! The judge finally pounds on his gavel calling for order as he looks accusingly at the grocery store manager. "What is the meaning of this?" screams the judge, red-faced with anger.

It does not matter to the grocery store manager that God did not dramatically appear. There is a different point to be made. With utter sincerity, the grocery store manager turns and appeals to the judge saying, "Didn't you feel it? Just for that one moment, in spite of everything, during that split second after I called God to the witness stand, wasn't there a sense that the impossible might happen? That God himself might walk through that door? Didn't you feel it?"

> *...I keep thinking maybe there could be that miracle! Maybe, just maybe there will be that cure out there...*
>
> *(Anna)*

> *... You know my viral load had been up to like a million or something. Then when I got started on these new meds and it brought it way down. That was hope. That was a whole lot of hope. I was like, okay, it is possible, you know? Then when my doctor said it was undetectable I thought all right!, Anything is possible, you know? It was almost as if the virus didn't exist! I thought, maybe it will happen you know, a cure!?*
>
> *(Vanessa)*

From the beginning of the epidemic people have hoped for a cure to AIDS. And from the beginning of the epidemic it seemed possible, if not probable, that a cure would come sooner rather than later. We were, after all, living in the United States, the richest country in the world with remarkable scientific and technological resources at its disposal. Many believed and hoped that the cure for AIDS would be found before their own deaths. During the 1980's the media regularly touted the latest breakthroughs pointing to a cure for AIDS. Twenty years into the epidemic, a cure for AIDS has not been found. Nevertheless, "hope for a cure" was among the first responses voiced by each participant in relation to hope.

The experience of hope as *impossible possibility* differs from wishing, or desiring. Christa states, *"hope is wishing for something so hard that it becomes true"* and honestly believes that she will "beat this thing [AIDS]." This paradox is at the heart of the experience of hope. When one hopes, probabilities do not matter; neither do the statistics. Marcel (1978) explicates the paradox by saying, "In a sense hope is not interested in the *how*: and this fact shows how fundamentally untechnical it is, for technical thought, by definition, never separates the consideration of ends and means" (p. 51).

In other words, whether something is literally or realistically possible is not the concern of hope. In fact, the moment probabilities become *unrealistic* is precisely the moment hope begins. For example, after days of searching frigid seawaters for survivors of a boating accident, a radio commentator says, "We are beginning to lose hope of finding any survivors." The expression *beginning to lose hope* appears here to mean *there will be no survivors*. Use of the expression however belies a deeper truth: when probabilities end, hope begins! In this case, the possibility that survival is unlikely means that hope for survival is all that is left. When there is no evidence, no proof, nothing material to cling to, people still hope. That is the paradox of the hoping experience. "...True hope...has not a grain of sense or of logic except when the worst is considered certain." (Ellul, 1977, p. 194).

...I'm not going to hold my breath, but there could be a cure for this, so that we don't have to keep taking all these frickin medicines. I still think I'll live to be a ripe old age, have my own business and do lots of travelling!

(Christa)

One feels Ellul's (1977) passion as he conveys the 'impossible possibility':

> [hope] is the passion for the impossible. It makes no sense, has no place, no reason for existence, except in the situation in which nothing else is actually possible. What it calls for is not a person's last resort, nor some second breath, but a decision from without which can transform everything. It exists when it is up against a stone wall, faced with the ultimate absurdity, the incurable misery. Thus it never expresses itself through a concurrence of means, but through the absence of means (p. 197).

Dutch author Liza Stilma's writings capture the depth of human complexity and emotion exhibited in the most ordinary circumstances. Stilma's poem, translated into English as "Francis" could alternatively be titled, *Hope: The Impossible Possibility*:

FRANCIS

When is it Saturday? Tomorrow? Today?
The question dominates his life, embraces all, and sparkes as the sun
Tomorrow?
No!
Today?
Not either. But when is it?
"You have to go to bed twice, get up twice, shave twice, and then it is
Saturday," they tell him
The morning arrives upon which everyone who is will to answer
the eternal question, says:
"Frans, now it is Saturday"
Unstable legs, as those that belong to Frans, can move miraculously
Fast!
Very early in the morning he is waiting for the bus
And with eyes brimming with hope he watches the door of the bus
as it swings open
Men, women, children, coming to visit at the institution
But no one says" "Hello Frans!"
No reason not to longer cherish hope: for anything more precious
Than hoping does not exist for Frans
And the most precious you hold on to all your life
The joy of it being Saturday cannot be taken away by anyone
And there is nothing that can dampen it

Joy because of the father who is sure to step out of the bus fill
Fran's life,
And the voice that will say: "Hi, my Frans," will be there some day
Of that he is sure
"He'll bring me a watch," Frans knows with a confidence that stands
firm as a rock that has defied the years
And as always, when telling his joyful story, he taps with his right
Index finger on his left wrist: That's where the watch will go
Sometime... one day
This Saturday too, passes
The last bus arrives without mercy and leaves without the father
Who was expected to step out
No reason to feel bad!
No reason to despair
There will be more Saturdays!
When is the next Saturday again?
Seven more times going to bed?
Seven more times getting up?
Seven more times using the shaving brush?
Then it will be Saturday
Then comes...
Then he will bring...

(Stilma, 1985)

To claim that hope is the *impossible possibility* is to embrace the incongruities held within the experiential. In the poem "Francis", each week the child waits for a father to appear. We don't know whether the father is alive or dead, whether Frans has ever seen his father or whether the father has ever arrived on the bus. The absence of details accentuates Francis' hope. These practicalities do not matter; "Saturday" will come. This is the mystery of hope: the impossible possibility. Where all probabilities point in one direction the *experience* of hope ignores probabilities. The experience of hope provides a nudging, irrefutable sense that something *else* will occur, or may occur, even though highly improbable. To use Aikman's (1995) words, "[Hope] insists on saying 'yes' about things when circumstances are shouting 'no" (p. 122).

> *...Hope is, like, a good feeling. I don't know, it's a good feeling. It's a feeling that there are possibilities... things are possible... all things are possible... even a cure for AIDS!*
>
> *(Vanessa)*

Hope: Moving Toward the Light

... well, when they told me I had AIDS, I felt hopeless, what was I gonna do? I felt like I was gonna die... But I didn't want to see nobody; I didn't want to talk to nobody. I just wanted to be left alone, to sit in the darkness... but once they backed off and left me alone, I was just like, O.K., time to get up out of this space and start doin' sometin... I realized I wasn't going to die so I might as well start tryin' to live, while I'm here, while I'm able...

(Vanessa)

... Before I used to get drunk, Now I start calling people to talk to them when I'm depressed. If I just sit and don't do nothin', I'll dig myself a hole and then I wouldn't come out. I have to do something now, for myself and because of [my child]. It's not fair to him for me to wallow and whatever... If I do somthin', that's like, well, hope!"

(Christa)

Functioning as a noun, the word hope can be viewed as a commodity one can either possess or do away with: one has hope; one loses hope; one gives or receives hope. The experience of hope, however, may be more allied with hoping, a verb. That is, hope is something one *does* rather than possesses. Instead of staying in a depression Christa says, *"I have to do something now"* and phones a friend. Similarly, Vanessa claims to experience hope in the moment she says to herself, *"OK, time to start doin' somethin'... "* How is doing something part of the experience of hope? Christa put it this way: *"I get depressed, but I don't dwell on it, I try to get over it by thinking about other things. Because, if I just sit on it then it just gets worse."*

The active component of hope is reflected in the ways the women describe their experience of hope and in the words chosen to portray the experience: *"So now I look at it like, what kind of things can I do to stay healthy and to be able to keep living as long as I can... "* ; *"I want my children's lives to be better than mine... "* ; *"OK today's a new day and I'm going to do something, I'm going to have fun... "* For some, the experience of hope is part of what happens 'on a good day', when one feels great and is "doing something": *"having fun, laughing, getting everybody all fired up... or playing with my nephews"*. This takes place in contrast to the *"... days you just sit at home and don't talk to anyone or see anyone. Those are the bad days."* Action

words alluding to the experience of hope include those having to do with empowerment, initiative and movement. Other action-oriented words such as trust, change, taking control, accomplishment, setting and meeting goals are part of the experience of hope.

In contrast to hopelessness, which is marked by immobilization, hope is something one does, or chooses:

> *... When I was in that place of hopelessness I kind of said to myself, now wait a minute, do I really want to stay here? Or am I going to get up again and start livin'... you know?*
>
> *(Vanessa)*

Christa acknowledged the reality of depression. Nevertheless she did not dwell on her sadness. She tried to 'get over it' by thinking about other things, phoning her friends, and doing something about her depression. Christa's words were, *"If I just sit with the depression it won't help matters at all."* For herself and for the sake of her child, she acted in some way to prevent herself from *"wallow[ing] and whatever."* This was not a passive concession. Recognizing the possibility of despair, she made a conscious effort to ward off depression and make a change; Christa did something.

> *The mind is its own place, and in it self*
> *Can make a Heav'n of Hell, a Hell of Heav'n*
>
> *(Milton, 1667)*

By emphasizing the mind as a place of both heaven and hell, poet John Milton appears to give privilege to one's cognitive resources. Can one *choose* to make of something a heaven rather than a hell? If hope is *something we do*, then is hope a choice? Can one refuse hope?

Certainly the experiences of hope as shared by the women in this study hinted at this cognitive dimension of hope, although their decisions for hope also encompassed other dynamics. As described by the women in this study hoping had to do with something beyond the cognitive. Decisions incorporated a yearning component: a longing for life, an inner-energy working in tandem with the cognitive. Perhaps this inner drive can best be described as that which propels

and prods the person towards life. This inner drive/cognitive dialectic was demonstrated in the following quotes, which showed a refusal to give in: *"I can beat this thing:" "I'm not going to die so I might as well start trying to live;" "I'll just keep wishing so hard until it becomes a reality."*

A newborn whale rises from its immersion in water to take in its first breath of air from above. Instinctively it rises to the surface, moving toward life. This is not a learned behaviour nor does that first breath come as a result of a thought process. It is the mammal's *character*; indeed, it is a matter of survival. Hoping, as an active process of doing something may well be as critical an act of survival as that baby whale's first swim to the surface of the water. Hoping/doing may make one feel more a part of life: "...[hope] is the only decisive, effective, conclusive and radical act..." (Ellul, 1977, p. ix).

Hope: A Present Light

After a horrifying (and near fatal) automobile accident, Grace experienced hope differently than she had prior to the disaster. Describing her post-trauma experience of hope, Grace repeatedly used words expressing an inwardly felt serenity and a previously unfamiliar sense of calm: *"I just knew everything was going to be all right."* In Chapter Five I used the phrase "an inner knowing" to portray one dimension of Grace's experience of hope. The same dynamic was strongly present in Vanessa's experience of hope and, to a somewhat lesser degree in Christa's experience. Conspicuous by its' absence in both Chantal and Anna's experiences of hope, this theme became a significant thread woven into the tapestry of hope. I have named this thread *Hope: A Present Light.* The word 'present' allows for discussion of the time orientation of hope. Paired together, *A Present Light* describes a deeply felt and distinct (although at times fleeting) characteristic of the experience of hope.

Hope: A Present Light emphasizes that the experience of hope is a sensation having little or nothing to do with the future or the past. It is not tied to anyone or anything. It is simply felt

and known in the moment. In fact there is a *timelessness* about the experience. To use Grace as an example, her experience of hope held deep meaning for her. It didn't matter if she died in two minutes or two years from then; the experience was deeply felt.

When *Hope: A Present Light* is experienced, there is a deep inner sense of serenity, of believing/knowing that 'all is well':

> *... There is something within me that feels it... I mean, when I look at where I was and where I am now I know that I have changed, my whole attitude. ... there is something within me, even to say I have peace with this, and with life... I just feel it... everyday. It is just hope...*
>
> *(Grace)*

> *... You just know it, that's all. To me its like, when its happenin' its hope, nothin' else, nothin' more and nothin' less. You just feel like it's all gonna be OK. No matter what, it's all OK...*
>
> *(Vanessa)*

What does it mean to feel deeply that, no matter what, everything is going to be 'OK'; what does it mean to hold that kind of serenity deep within the psyche? Like a child being tucked safely into a cozy bed, *Hope: A Present Light* portrays the feeling that all will be well. Perhaps the outward signs point to disaster, but inwardly there is a sense of certainty and felt assurance that transcends the particular realities facing us. We let go, giving over to something larger than the circumstance or situation, experiencing oneself as part of the totality of life.

I see trees of green, red roses too;
I see the moon, for me and you.
And I think to myself, what a wonderful world!

I see skies of blue, and clouds of white;
Bright blessed day, dark sacred night.
And I think to myself, what a wonderful world!
(Murray, 1999)

Hope: A Present Light to some may be represented by the sweet, simple tune "It's a Wonderful World" made famous by the raspy voice of Louis Armstrong. Indeed the song does capture a sense of carefree contentment in the present. Similarly, the experiences of hope represented by *Hope: A Present Light* convey the feeling of contentment. Nevertheless,

experienced within the context of HIV/AIDS, the feeling of contentment occurs in the midst of hardship. Could this be akin to the "freeing hope" described by Moltmann (1974):

> The prisoner experienced an inner conversation when he gave up hope of getting home soon, and in his yearning he rediscovered that deeper "hope against hope." Hope made him free to accept, even laugh at the barbed wire, and to discover in his fellow prisoners human beings whose company he enjoyed, with whom he could be happy even in suffering... But the hope that was born there [in prisoner of war camps] was not that painful, disturbing hope, but rather a deeper, liberating hope which works through love ("Forward").

Moltmann's description implies that there are levels of hope: a hope that yearns for something and a hope that is freeing, "liberating", in spite of the realities of captivity. He compares a painful, disturbing hope with another kind of hope, which he claims is deeper. One can only get in touch with the deeper hope by letting go of the other, the yearning hope. Perhaps this is the same as Marcel's description of hope as "relaxing into non-acceptance" (1979, p. 38). Imagine a skier coming down a difficult slope. The more relaxed the skier can be, the less struggle there is against the hill. The movements seem effortless, in spite of the precipitous nature of the slope. So it is with hope. One experiences the deeper liberating hope when one goes with the rhythm of the trial, which involves an element of patience and trust. We wait for hope, but in the waiting we experience *Hope: A Present Light.*

I said to my soul, be still, and wait without hope
For hope would be hope for the wrong thing; wait without love
For love would be love of the wrong thing; there is yet faith
But the faith and the love and the hope are all in the waiting.
Wait without thought, for you are not ready for thought:
So the darkness shall be the light, and the stillness the dancing.
(T.S. Eliot, Four Quartets)

Conclusion

In this chapter, five threads have been named and explored: *Hope: In the Company of Hopelessness; Hope: An Inner-Outer Light; Hope: The Impossible Possibility of Light; Hope: Moving Towards the Light* and *Hope: A Present Light.* Woven together, these threads create a tapestry of hope, a new portrayal of hope created by the interweaving of these threads.

Because I am calling upon visual images, it is helpful at this point to revisit the diagrams presented at the beginning of this chapter. Figure G depicted the participants' individual experiences of hope together in a holistic representation of the experiences of hope. Figure H depicted the five common threads explored in this Chapter. The following diagram depicts two of the diagrams juxtaposed: the women's figures and the common threads:

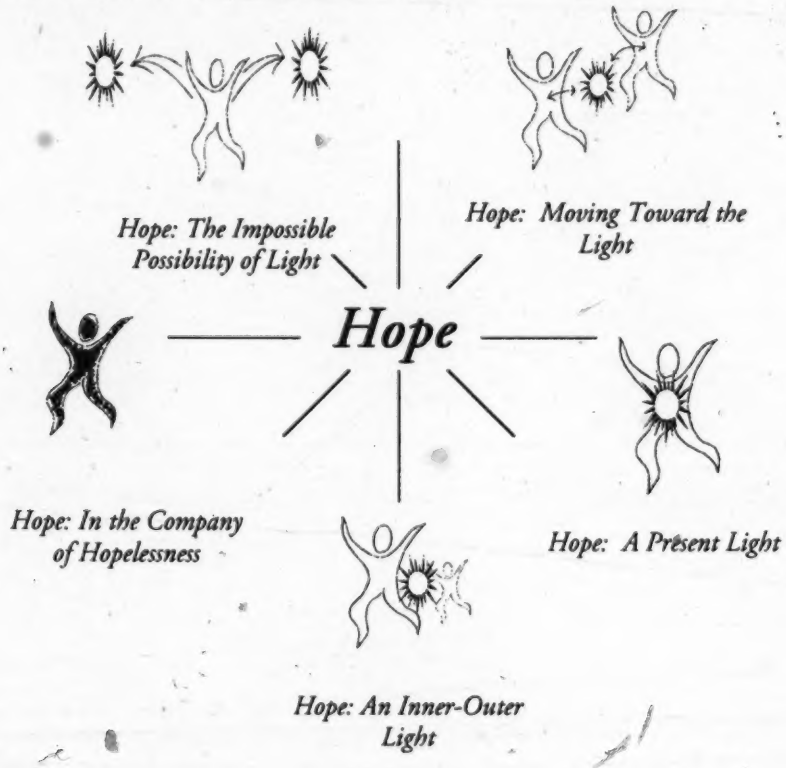

Hope: The Impossible Possibility of Light
Hope: Moving Toward the Light
Hope
Hope: In the Company of Hopelessness
Hope: A Present Light
Hope: An Inner-Outer Light

Figure I: A Composite Picture of the Experience of Hope

I have found it useful to look at the diagram as if peering through a kaleidoscope. In order for a kaleidoscope to work, one must focus on something – an object or scene. With a slight twist of the kaleidoscope, the many pieces of the picture fall together and apart. One knows the object for what it is and one sees that same object 'differently'. So it may be with the experience of hope. Each of these themes is a component of the experience of hope, while no one of the themes in particular presents the fullest expression of the experience. The experience of hope may, at one time or another, be each of these themes and all of them together. As we turn the pieces—that which has been shared about the experiences of hope—over and around, we see different portrayals of hope. Just as we understand one of it's components, another takes shape before our eyes. As the individual themes overlap and intersect, a richer picture emerges, one that is multilayered and dynamic:

> It is especially important not to separate those different themes of hope. It is important not to divide them, not to do a content-analysis on hope. That would be to ruin it, to distort it, to give it a meaning which it does not have, to kill it. That is to say that, if we think to lay hold of it by its object, we lay hold of exactly nothing, because it is only movement and life (Ellul 1977, p. 169).

CHAPTER SEVEN

A TAPESTRY OF HOPE

This research is based on conversation. In a literal sense, I began in direct dialogue with each of the participants. Subsequently, I have been 'in conversation' with their *experiences* of hope—interpreting them in dialogue with others' and my own experiences of hope. In this final chapter, I revisit the common threads of the collective conversations with my participants, with the literature, and with my experiences of hope. Under the heading 'weavings' possibilities for further research are offered in relation to each common thread. The conversation continues as I revisit the theoretical foundations of feminism, human ecology, and phenomenology and offer suggestions for hope research utilizing these perspectives. This chapter is woven around the description of a mixed media forty-one inch by fifty-six inch quilt, which was created separate from, but in tandem with this project. What follows is a description of the quilt and some reflections presented 'in conversation' with the visual representation of this research, the quilt.

The Quilt

From the very beginning I have felt the need to incorporate something aesthetic into this project. Midway through the research process, I shared with a friend my interest in creating a visual portrayal of the themes and intricacies of the research. As a gifted quilter, Mary was intrigued by my ideas and offered to help design a "quilt of hope". Over a series of meetings, I described the project in great detail to Mary and offered her key parts of the manuscript to read. Specifically, she was given the written descriptions of the women, their experiences of hope and each woman's 'snapshot of hope'.

Originally completion of the quilt and completion of my writing were to coincide. Needless to say the quilt was finished months ahead of my writing schedule! However, these divergent completion dates became a true gift to me. I hung the quilt over my working space where it provided me with both inspiration and hope. Having the visual display of this research

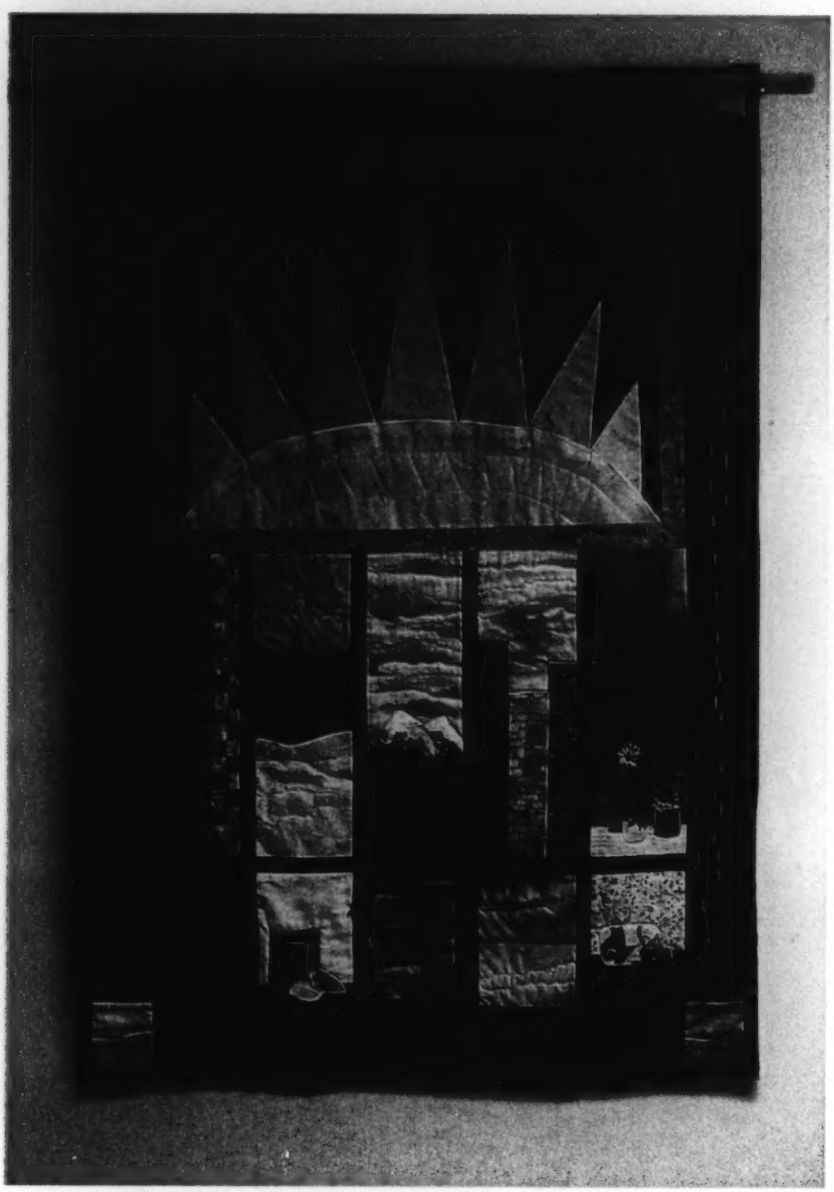
within eyesight helped me to stay focused on the five women's experiences of hope and to keep alive the many connections inherent in this project. Additionally, the quilt stimulated a renewed sense of wholeness regarding the participants' experiences of hope, the research process, and the project itself. With the quilt in front of me, I was able to see the project in its entirety and relate the various parts to the whole.

I looked at the quilt often as I recalled my conversations with the women, wrestled with concepts, searched for the most suitable words to convey my thoughts, digested committee members' comments, or pondered philosophical or theoretical notions. In the presence of the quilt, I was drawn to reflect more deeply about hope—and to *experience* hope—Chantal's, Vanessa's, Grace's, Anna's, Christa's and my own.

The five themes portrayed in Chapter Six depict threads common to each participant's experience. Interestingly, each of the five themes was strongly represented by a particular participant's individual experience of hope. For example, *Hope: in the Company of Hopelessness* was a thread common to all five participants' experiences of hope. However, it was *Chantal's* experience that seemed particularly representative of this theme. Likewise, Christa's overall experience of hope was especially illustrative of the theme *Hope: An Inner-Outer Light.* Consequently each theme depicted on the quilt also represents one of the five participants.

Like all quilts, this one is comprised of many parts. Five rectangular 'windows' portray each participant's 'snapshot of hope' as described in Chapter Five of this dissertation. Below and separate from each window is a small square representing salient features—the foundation—of each of the participant's hope. Together the window and foundation square form a panel portraying both the individuality of each participant's experience of hope and the corresponding theme. Each of the five windows stands alone; nevertheless there is an overall harmony to the depiction. Like looking out of a bay window, one complete picture is presented, though comprised of five different parts.

A deep purple fabric borders each panel and foundation square. Three bluish-green interwoven strands of fabric are a part of the outside border: another frame of purple, which holds the quilt together. The predominant image on the quilt, comprising a full one-third of the space, is a brilliant yellow-orange sun with its' rays emanating outward.



Photograph #2: The Quilt

Putting the Pieces Together

The Sun

With its bright orange-yellow colour and rays jutting outwards and upwards, the sun dominates the quilt. The strength of the image emphasizes the centrality of light as the overarching symbol of hope for the women in this study. The image of light—specifically sunlight—captured the experience of hope for each of the participants. Grace's experience of hope was described as the dance of the sunlight through her kitchen window. For Anna, the sunlight shining on the top of a mountain represented perfection and hope. Although experiencing a night of physical discomfort and restlessness, as the morning light came, Vanessa experienced hope, making an otherwise ugly scene beautiful. And, with her distinctive clarity Christa said, *"The light on the snow is just clean, like a renewal . . .and that's hope!"* These images of hope contrasted with the 'darkness' of hopelessness. The darkness was also described and experienced by each woman, but mainly represented in this research by Chantal.

The strength of the image of light came as a surprise to me. As the women spoke and built upon the image, however, I considered how common and powerful images of light and dark are to describe hope and hopelessness. Marcel's (1978) poetic use of dark and light to describe hope is but one example:

> [Throughout the time of trial or captivity] one is deprived for an indefinite period of time, denied a longed-for light... The less life is experienced as a captivity the less the soul will be able to see the shining of that veiled, mysterious light, which...illumines the very centre of hope's dwelling-place (p. 30-32).

The Five Panels

Hope: In the Company of Hopelessness

The first window of the quilt depicts the theme *Hope: In the Company of Hopelessness.* It is presented as a series of small squares: shades of grey placed in succession. This window is a powerful presence on the quilt, as it depicts both hopelessness and the possibility of movement or change. Like a glass half-full or half-empty, one can look at this panel two ways. If one reads the panel from left to right the coloration of the panel moves from dark to lighter shades of grey. If one reads the panel from right to left, however, the shading shifts from light to dark. How like the experience of hope this is! The experience of hope emerges from within the grey areas of life: when confronted with deep questions of meaning; in times of illness; in times of hardship; in the presence of death. Each person confronts and manages the grey areas differently; some will move toward darkness (deeper into hopelessness) while others will move toward the light (hope). Some, like the participants in this study will move back and forth, *In The Company Of Hopelessness.*

Looking at this panel, I am reminded of my first and only visit with Chantal. I remember the darkness of her apartment, the palpable feeling of hopelessness while in her presence, the precarious quality of her descriptions of hope, and the many questions still left by her disappearance. The shades of grey contained within this panel convey the ambiguity of Chantal's experience of hope.

Each of the women in this study experienced hopelessness and contrasted the darkness of hopelessness with the light of hope. The theme *In The Company Of Hopelessness* conveys the twofold reality of the experience: a) the coexistence of hopelessness and hope and b) the easy

return to hopelessness. Positioned alongside the other panels, this panel affirms the ever-present reality of hopelessness *even while* experiencing hope. With its grey hues and sequencing of squares, the light and dark of this panel are in perfect balance. The shading conveys both the possibility of movement away from (or closer to) hopelessness and the interactive relationship between hope and hopelessness.

The foundation square underneath the window panel reveals a deep blue night sky speckled with stars. This square represents a fundamental paradox held within the experience of hope and HIV/AIDS: life in the midst of death. Looking at this square of darkness I am reminded of the sadness caused by AIDS—the immeasurable suffering, the sting of injustice and the incredible loss of life. To me each star in that dark sky represents a human life—a light that no longer shines on this earth. *At the same time*, each star represents those who are still living with HIV/AIDS and the (at times distant) light of hope. Despite the darkness, it is possible to see great beauty in this square.

Revisiting The Literature

The relationship between hope and hopelessness is a common yet undefined thread throughout the hope literature. Within the women's experiences are echoes of the two predominant themes about hope and hopelessness found within the current literature: first, that hopelessness is a precursor to hope (Marcel, 1978; Pruyser, 1963; Vaillot, 1970), and, secondly, that hopelessness is the opposite of hope (McGee, 1984; Stotland, 1969). The former belief is represented by Marcel's (1978) proclamation "the truth is that there can strictly speaking be no hope except when the temptation to despair exists" (p. 36). Representing the second view (that hope and hopelessness are opposites), nurse researcher McGee (1984) described the contrast in this way: [with hope] a person acts, achieves, moves, and plans futuristically and assertively. Without hope, the person is dull, listless, moribund, present oriented, and hostile. Hope implies freedom, adaptability, control, and imagination, whereas hopelessness connotes entrapment,

helplessness, and impossibility (p. 38). Alternatively, attempts have been made to distinguish hopelessness from other concepts such as despair (Ellul, 1977); helplessness (Cousins, 1989) and apathy (Campbell, 1987).

Other researchers have offered descriptions of hopelessness and hope in a way that suggests a more fluid relationship between the two. Nekolaichuk (1990), for example, placed the hoping process within a hoping network, including the two concurrent processes of *learning to live with uncertainty* and *maintaining the hoping self.* Similarly, Dufault & Martocchio (1985) concluded that confidence and uncertainty reflect differ[illegible]dimensions of hope and, thus, can coexist in the hoping person: ". . .hope and hopelessn[illegible]ot the opposite ends of one continuum nor is hopelessness the absence of hope. [illegible]here or dimension of hope is always present" (p. 389). According to Laskiwski and [illegible]spair was a part of the hoping process, essential to the modification of hope and learning acceptance.

Going one step further, and more closely aligned with the findings in this study, Wang's (1999) phenomenological study of hope among people with Leprosy in Taiwan described the relationship between hope and hopelessness in this way:

> No participants fragmented the experiences of hope and despair into two distinct, linear entities at a point where one ends and the other begins. Rather, they shared a vision of being at peace at last while glimpsing the despairing moments. As such, hope and hopelessness coexist and interplay in a rhythmical process, going beyond the boundary of space-time to multiple realms of the universe in what was, is, and will be all-at-once. (p.159)

On the quilt, the small grey squares in various shades present a visual portrayal of the relationship between hope and hopelessness as conveyed through the current literature. There is both diversity of opinion within the field and still much to be revealed about the relationship between these two important constructs.

Weavings

A correlation can be made between the findings of this research and prior assertions regarding the relationship between hope and hopelessness. First, each of the participants in this study experienced hopelessness within a 'time of trial' such as when diagnosed with HIV infection (or AIDS), when struggling with addictions, when experiencing loss, or when facing death. This confirms prior assertions that hope begins when an individual is confronted with difficulty--'a tragic situation' (Keen, 2000; Marcel, 1978; Morse & Dobernek; 1995; Pruyser, 1986). Secondly, the centrality of the experience of hopelessness confirms its importance to the study of hope. Additionally, by using the contrasting images of light and dark to describe hope and hopelessness the women's descriptions of their experiences correspond to a certain degree with those researchers who claim that hope and hopelessness are antithetical.

This exploration revealed however, that while contrasting images such as light and dark helped differentiate the two, the experience of hopelessness and hope seemed to parallel rather than oppose each other. Hopelessness was carried close to the surface; the acute memories of hopelessness meant the participants could easily access the experience. The women in this study lived *In The Company Of Hopelessness.* At any time, something could happen to prompt a sense of hopelessness: a change in blood counts; medications no longer working; a diagnosis of AIDS; or even (simply) waking up and having a bad day. As these women walked the tightrope between the known and unknown, they walked in the company of hopelessness. Consequently, hopelessness was indeed part of the constellation of the hoping experience, the two coexisting in a way that has not been adequately described in the current hope literature.

One image that comes to mind to describe *Hope: In The Company Of Hopelessness* is that of two paralleling sets of train tracks—one representing hope, the other hopelessness. Along the way are a series of junctures allowing the back and forth between tracks. At any time, something can trigger the switch taking one from hopelessness to hope or vice versa. What is it

that triggers the switches between the tracks? What causes the move from the track of hopelessness to the track of hope?

Phenomenological explorations of the lived-experience of hopelessness (and despair) might illuminate the nuances of difference-sameness brought forth in this study. In the context of HIV/AIDS these explorations might take place either at critical junctures in the progression of HIV disease (e.g. time of HIV positive diagnosis; a drop in T-cell count or increase in viral load; time of diagnosis with AIDS; or at the onset of symptoms) or at particular times of stress (e.g. loss of a loved one; experiencing HIV/AIDS-related prejudice; end of a relationship; pregnancy). Explorations focused on these questions would provide additional insight into the relationship between hope and hopelessness.

Hope: An Inner-Outer Light

The window panel of the quilt representing the theme *Hope: An Inner-Outer Light* is a simple scene. In contrast to the ambiguity depicted on the first panel, this one leaves nothing to the imagination. The shiny silver thread used to outline the trees produces the effect of glistening snow and gives a tangible quality to the icy snow scene. This panel is designed to capture the clarity with which each woman named the *outer things* prompting the inner experience of hope: friends and family members; children; God or Jesus; the printed word; and scenes from nature. The specificity of Christa's description of hope makes her experience most representative of this theme. The panel Depicts Christa's snapshot of hope: *"I saw the sunlight on the snow in the trees and I just knew my test results were going to be OK."*

This panel's foundation square portrays a seashell, a crystal, and a framed picture of a child. The child in the photo is actually my quilter friend's son, but represents the boy so central to Christa's experience of hope. That is: hope *is* Christa's child! Everything in both the window panel and the foundation square is depicted in great detail, or outlined, to accentuate the clarity and definitive character of this theme and Christa's experience of hope.

While writing one day, I looked around my workspace (which by then had overtaken the dining room of my home). I noticed that I had arranged the space to include special things: fresh sweet peas in a tiny vase; a seashell; a recent picture of my new godson (smiling at his auntie!); and a painting purchased for me midway through my writing, reminding me of a favourite camping spot. Along with these was the quilt, hanging in a prominent spot for my contemplation. Inadvertently over the weeks, I had brought these items into my working space. While contemplating these special things around me, I realized that I had surrounded myself with items which helped *me* feel hope. Like Christa, Vanessa, Chantal, Anna and Grace, I too needed reminders of hope in my midst: items reminding me of people, the earth and love—those things *outside* myself that prompt an *inner* sense of hope.

Originally, the photo on the quilt was to have been a child on a swing, viewed from behind so the identity of the child would be unclear. I later agreed to incorporate the photo of Mary's (the quilter's) child. From time to time I have reflected upon that decision. Christa's hope was so unequivocally linked with *her own* child that introducing another child on the quilt seemed a betrayal of sorts. However, all of the women in this study experienced hope in relationship with a *particular* someone or something. In Christa's case it was her son. The other participants were equally specific. Anna's father, Vanessa's friend, Chantal's social worker, and Grace's grandmother were each named as a *specific link* to the experience of hope. The same is true of my experience; my hope is linked with specific people and places. As you read this, perhaps you too will be inspired to name the things or people outside of yourself, which stir an inner sense of

hope. Thus, instead of being troubled by it, I have come to appreciate the specificity emphasized by the photo on the quilt.

The photograph of the child in Christa's foundation square is important for another reason. Incorporating a photograph into the quilt acknowledges the photographic dimension of this research, which was both innovative and added depth to the study. Generally photography is unambiguous; photographs are specific. Certainly the photos taken by the women as part of this research depicted specific things, scenes and people: outward signs representing the inner experience of hope. Moreover, photographs themselves can represent the interplay of inner-outer dynamics. A photographer is motivated by something 'outside', which stirs an 'inner' response and results in the taking of a particular photo.

Revisiting the Literature

The second theme *Hope: An Inner-Outer Light* can be found reflected in existing hope literature in a variety of ways. Hope has been explored as both a developmental process (Erikson, 1964; Lynch, 1965), and as a trait of an individual (Grimm, 1984; Nowatny, 1989). Moreover, hope has been associated with a sense of meaning and purpose (Frankl, 1959; Menninger 1959; Vanier, 1971), a longing for something better (Cousins, 1989), a "life wish" (Keen, 2000), and "vital because [hope] can mean the difference between happiness and sadness, maybe even death of the spirit"(Smedes, 1998, p. 76). These foci attest to an understanding of hope as an *internal* construct.

Concurrently, researchers maintain that although hope is personally significant and individually experienced, hope cannot sustain itself on its own; hope is dependent upon spiritual, physical, emotional or social resources (Frankl, 1959; Jevne, 1991; Miller, 1985). Jevne (1991), for example, claims, "Hope may lie in a purpose, a goal, a person, a procedure, a theological belief, our families" (p. 151). These outer resources are given and received; and within the reciprocity of interaction, hope is experienced:

> The language of hoping does not accentuate action verbs, but verbs of relationship and receptivity. A hope is *found*, it is *given*, it is *received*. One hopes with through and sometimes for someone else. Hoping is basically a shared experience (Pruyser, 1963, p. 95).

Many researchers affirm the shared nature of hope. Lange (1978) states that "[hope] generally involves another person or a belief in a higher being or purpose" (p. 173). Nekolaichuk's (1995) exploration of the meaning of hope uncovered the interpersonal dimension of "authentic caring" as one of three components in the structure of hope, while Jevne (1991) states unequivocally, "hope is given and received through human relationships" (p. 149). There is broad agreement in the literature that hopefulness is an internal quality influenced by external others or resources (Byrne, Woodside, Landeeen, Kirkpatrick, Bernardo and Pawlick, 1994; Herth, 1993; Hinds, 1990; Hinds & Gattuso, 1991a; Miller & Powers, 1988; Rait & Holland, 1986). A study of hope among homeless people revealed findings consistent with previous findings. Namely, "the most frequently identified sources of hope have been family, friends, health care professionals and God (or a higher being)" (Herth, 1993, p. 342).

There is strong support in the literature regarding the spiritual component of hope, not only from those asserting a faith perspective (Frankl, 1959; Fromm, 1968; Havel, 1991; Lynch, 1965; Marcel, 1978; Merton, 1969; Moltmann, 1975, 1967; Kierkegaard, 1980) but from a clinical perspective as well (Cutcliffe, 1995; Farran, et.al.1995; Hinds & Martin, 1988; Jevne, 1991; Menninger, 1959; Miller, 1989; Nowatny, 1989). Borrowing Martin Buber's (1970) doctrine of "I-Thou", Marcel expounds on the relational component of hope. For Marcel, the I-Thou relationship is the source of hope, and even more specifically, the I-Thou relationship between an individual and God. This is the paradigmatic, foundational relationship of hope extended among humans. The relatedness critical to hope is rooted in receptivity and love: "I hope in Thee [you] for us" (Marcel, 1978, p. 60).

Lynch's (1965) psychology of hope also touches on the inner-outer theme, as for Lynch, hope and help are inseparable: "Hope is truly on the inside of us, but hope is an interior sense that there is help on the outside of us" (p. 40). The consensus throughout the literature appears to confirm that whereas despair is a solitary experience, hope consists of communion and reciprocity.

Weavings

I have noted the strong correlation between various relationships and hope as conveyed through the literature. Nevertheless, researchers have been unable to adequately explicate both *how* hope occurs within relationships and what comprises the nature of the interactions which prompt, instil, or nurture hope. Neither have we adequately portrayed what those hopeful experiences or hopeful relationships are like.

Hope: An Inner-Outer Light addresses companionship, love, and a deep connection with God or others. It reflects the social character of what it means to be human, the intimacy of interactions, and a certain mystery at the heart of those interactions. Why, for example, are some (hopeful) connections made between individuals at a particular time? Just how and why do such things as a phone call from a friend, a time of meditation or prayer, certain written phrases, scripture passages, pictures or songs inspire us at a particular moment?

This exploration accentuated the dynamism, reciprocity, and necessity of relationships in the experience of hope. It was beyond the scope of this investigation to describe the qualities of those relationships that inspired or initiated the experience of hope. Nonetheless, notable characteristics included consistency, trust and presence or availability. Certainly the relationships were not dependent upon proximity or familial connection (e.g.Chantal's social worker), but rather a deeply felt connection.

Hope: An Inner-Outer Light was strongly articulated in this study through religious expression: personal or corporate prayer; having faith; experiencing the presence of God (or

Jesus); reading passages from Scripture; attending worship services; and reflecting on the cross or other religious symbols (e.g. praying hands, a hymnbook). Further explorations into the spiritual characteristics of the experience of hope are warranted. People living with HIV/AIDS may represent a cross-section of religious traditions including those who have been estranged from mainstream Christianity.

This exploration confirms some dimensions of earlier research but goes even further, prompting more questions about the nature of the experience of *Hope: An* Inner-*Outer Light* and causal connections prompting this dimension of the experience. Questions still to be explored in relation to this theme include those related to the tangible 'items' that engender hope: what type of *things* spark the experience of hope and why? What kinds of relationships foster experiences of hope? What is the relationship between (various kinds of) spirituality and the experience of hope? What is the connection between the experience of hope and meditation, or prayer?

Hope: The Impossible Possibility of Light

The window panel of the quilt depicting the theme *Hope: The Impossible Possibility of Light* represents sheer perfection. A snow-capped mountain rises up from the tree-lined shores of a clear blue lake. The mountain peaks point upwards into an immense span of blue sky. It is a scene of perfect beauty and serenity. Below the mountain scene the foundation square depicts a thin rainbow cutting through a torrential rain. The window panel and foundation square stand in balance: the delicacy of the foundation square contrasts the sturdiness of the mountains in the window panel. Together the window panel and square are representative of Anna, who seemed ungrounded in the present, unable to experience hope except in relation to her past *(There's no place like home)* or as she dreamt of future perfection *(Somewhere over the rainbow).*

I have looked at these two representations often, reflecting on the wistful, dreamlike quality of Anna's experience of hope. As I look at this panel, I am aware of the wistful dreamlike qualities enveloped in my own experience of hope. There are aspects of my experience of hope that fall under the category *The Impossible Possibility*. My own experiences of hope encompass hoping for a cure for AIDS, the end of poverty, and the end of all forms of oppression. These hopes are intimately bound with my own belief that indeed *"all things really are possible"* (to use Vanessa's words). I believe and I hope that it is possible for humanity to live in harmony without exploiting each other, earth's creatures, or nature. As I've looked at Anna's panel, I've been challenged to reflect upon this dimension of my own experience. Are these unattainable desires, wishes without grounding in reality? Does this dimension of my experience of hope provide me with a vision and (thus) incentive to work for social change? Or, is this dimension an essential component of hope itself, represented by *Hope: The Impossible Possibility*?

Revisiting The Literature

A considerable amount of literature addresses the distinction between wishing, optimism and hope. Some contend that wishing is an important component of hope. Lynch (1965), for example, states, "Where there is no wishing there can be no hope" (p. 25). Likewise Smedes (1998) asserts, "we only hope for what we wish for" (p. 11). According to Smedes (1998), hoping begins by wishing for that which is better than what is. Others emphasize the differences between wishing, optimism, and hope or hoping. Acknowledging that wishing and optimism may be 'first steps' in the hoping process, Farran, Herth & Popovitch, (1995) nonetheless distinguish between the three by exploring the affective, cognitive, and behavioural components of each concept. Wishing, for example, involves an inflexible goal orientation (behavioural) and optimism a constricted stance with regard to painful feelings (affective). These characteristics contrast with hope, which is described as more open to painful feelings and flexible toward desired outcomes.

Dufault & Martocchio (1985) differentiate between wishing and hoping by stating the following: "A wish differs from a hope in that it is not perceived as within the realm of possibility in the present or future" (p. 385). And Gabriel Marcel (1978) makes a distinction between wishing and hoping by stressing that hope is less ego-involved, embracing a sense of patience that is not evident in wishing. The contrast between wishing and hope is underscored in the phrases "I hope..." and "I hope that..." (p. 32).

Another theme in the hope literature circumvents the issue of semantics by portraying hope as "...more than a calculation of probabilities. This 'not logical' aspect of hope is the aspect that is often the most difficult to understand and accept (Jevne, 1991). Similarly, Aikman (1995) claims, "Hope in many ways is paradoxical: It insists on saying 'yes' about things when circumstances are shouting 'no" (p. 122).

The picturesque scene on the quilt is dreamlike, almost unreal in its perfection. Nevertheless, as one gazes at the panel, the perfection *feels* accessible, capturing visually what hope literature has attempted to convey through words.

Weavings

Although it is helpful to delineate the characteristics of each concept as described in Farran, Herth & Popovitch (1995), in doing so, one risks detracting from the holistic understanding of the experience of hope, which includes dimensions of wishing, envisioning, and dreaming. If wishing becomes the sole focus of the experience, however, without encompassing the other threads of hope as described by the participants in this study, then the hoping experience is more fragile, more shallow, and more depleting of the individual's spirit. I think of Anna whose hope for life to "be the way it used to be" prevents her from dealing with the realities of loss and illness.

The part of the experience of hope referred to by the participants as a hope for a cure for AIDS (*The Impossible Possibility)* is neither a false hope nor a specific hope that may change

character when unrealized. On the contrary, though specific, this dimension of the constellation of the experience of hope and must be embraced for what it is: *The Impossible Possibility.*

Opportunities to explore *Hope: The Impossible Possibility* include: phenomenological explorations of the experiences of wishing, envisioning, and hope; explorations into the processes of wishing and hope; how these interact and motivate action or foster goal setting (and achievement); and explorations into the connections between visualization and the experience of hope.

Hope: Moving Toward the Light

The panel depicting the theme *Hope: Moving Toward the Light* is noticeably different from the others. It is striking for its subtlety, the questions it raises, and the paradoxes it portrays. The window illustrates the photo Vanessa described to me but was unable to photograph. After an endless night of nausea and sleeplessness, Vanessa had been moved by the gentle beauty of a sunrise which *"...even made the tenements across the street almost beautiful"*.

The window depicts three columns of brick and stone, contrasted against the soft, muted colours of dawn. The foundation square portrays night and day. Intertwined and yet distinct—like yin And yang—one is intimately tied to the other. Still, the meaning of this panel is not apparent. It is not clear what is being depicted, dawn? Or nightfall? Does the stony fabric depict buildings, or walls? What is on the other side of the brick and rock? What is the source of the light?

This panel contrasts with the others, which are more pleasing to the eye. When I look at this panel I am reminded of the fact that AIDS is not pretty. Like the rough neighbourhood around her neither is Vanessa's life pretty. Vanessa's experience of hope, however, facilitates an awareness or *sense* of beauty though the physical realities around her remain unchanged. It is this

same internal feeling that causes Vanessa's motivation toward action: *". . .Time to get up and out [of that place of hopelessness] . . .I'm not going to die so I might as well start trying to live!"* To Vanessa, this is the experience of hope.

This panel of the quilt has given me more moments of reflection than any of the others. The three columns of brick and stone to me represent the 'captivity' so powerfully described by Marcel (1978) and others as the beginning point of hope: that which prompts the experience. I have looked at those walls and thought about all the ways in which people are held captive, closed or walled off from that which might give or bring hope. I have wondered, in what ways are hearts hardened (like those brick walls) to the experience of hope through such realities as poverty, injustice, isolation and illness? Emerging from these is another question: what is it that facilitates one to 'see' the beauty—to see hope in places where it appears absent? To feel hope against all odds? Additionally I have thought of how Vanessa gets hope when she needs it or when she begins to feel hopeless. How does a person *get* hope? How do I get hope when I need it? What moves me toward the light of hope? These questions bring focus to the action component represented by *Hope: Moving Toward the Light.*

Revisiting The Literature

Pruyser (1963) made the following claim: "For where there is no hoping, the organism will not mobilize its resources to wage a valiant fight with the forces of illness" (p. 90). Marcel understands hope as the crucial first step towards overcoming the temptation to despair: "...Hope is the *act* by which this temptation is *actively* and victoriously overcome" (Marcel, 1978, p. 36 emphasis mine).

Jevne asserts that hopeful people are action-oriented: "There is an active component to hope. It isn't just something that finds itself in your soul . . , It is a force in our lives that takes us forward" (cited in Roset, 1999, p. 129). Jevne also calls upon individuals to "throw the hope switch" in order to complete the circuit and allow hope to take hold (Jevne & Miller, 1999). In

fact many researchers have explored the action component of hope (Averill, Catlin & Chon, 1990; Dufault & Martocchio, 1985; Farran, Herth & Popovitch, 1995; Korner 1970; Snyder, 1994; Snyder, Harris et. al., 1991; Stotland, 1969;). In a recent phenomenological study, Keen (2000) described hoping as comprised of underlying processes of intrapsychic change, the cumulative effect of which leads to a 'change-in-self'. Relying on visual imagery, Pruyser (1963) compares the activity of hope to steering a ship in a gale:

> Hoping is not an elegant drifting in leisure and comfort, as a tourist may do in a Venetian gondola. It is much more like steering a ship in a gale. It permits no departure from reality, otherwise it becomes illusion and delusion. (p. 92)

Weavings

What is it that initiates movement from the dark toward the light? And how does one access that part of themselves or others? The theme *Hope: Moving Toward the Light* gives emphasis to the reality that hope is something we do; it is a process, an activity, and an action. The dimension of the experience of hope described as *Hope: Moving Toward the Light* to emphasizes the *verb* qualities of hope as opposed to its usage as a noun: *hoping* rather than hope.

Hope: Moving Toward The Light speaks to the saying "yes" to life, generally taking place in response to someone or something. This dimension of the experience of hope is neither oriented to the future nor is it interested in attaining goals. Nevertheless it is active, responsive, and dynamic; it is not passive or reflective; it may be that which keeps one from giving up or giving in to a situation: the choice for hope.

As the embers of a fire begin to die, they often flicker and flare up before bursting into a final flame. The image is appropriate for *Hope: Moving Toward the Light.* This dimension of the experience of hope is akin to—a spark that burns and flares up, sometimes even coming as a last-gasp attempt to burst into flame and provide life to itself and others.

The obvious question raised by this theme is: why do some people move toward the light of hope (even under the direst conditions) while others do not? I think again of Vanessa, who is the most ill of the participants, faces the most difficult challenges of the participants (including racism), lives in the poorest circumstances and yet is able to *move toward the light*, to get hope (and give hope) when needed. In contrast, Anna has a job and familial support, has never battled addiction or lived in poverty and yet finds it difficult to relate to or experience hope. The contrast confirms that hope is a compelling life force that can flare up in spite of—and in the midst of—any circumstance.

Further explorations into *Hope: Moving Toward the Light* might include questions related to the process-nature of hope, the experience of hope in the context of actions, or the experience of *getting* hope or *giving* hope. Phenomenological explorations comparing the experience of hope with the experience of hoping could further illuminate this dimension of hope.

Hope: A Present Light

The window panel depicting the theme *Hope: A Present Light* is delightfully simple, portraying flowerpots on a windowsill. Pastel colours, the use of embroidery and fabric paints add to the cheerfulness of this panel.

When looking at this panel, I often found myself smiling and wagging my head in delight, reminded of Grace's experience of hope. At times her words sounded like they came from a Hallmark greeting card instead of from real life experience. But Grace's hope was anything but fake, or syrupy sweet. She experienced hope in the midst of a near fatal automobile accident; hope which she recounted as a sense of peacefulness, "*. . .I just knew that everything would be OK, [and] that life goes on and on and on . . .*" The picture Grace described to me to depict that experience was of the morning sun coming

through her kitchen window, shining light on her plants.

The window panel captures the lightness, the joy, and sense of peace most poignantly described by Grace. The flower pots, the kitchen windowsill, the play of the light and the spring colours contribute to the image. The foundation square depicts items that provided comfort to Grace: her grandmother's Bible and hymnal, the back of an easy chair with her grandmother's comforter thrown over it, and her grandmother's eyeglasses. The background of floral wallpaper adds to the cozyness of the scene.

The theme represented by this panel portrays the dimension of the experience of hope which is not easily described: an affective response, a feeling, an inner sense of knowing that all is, and will be, well. *Hope: A Present Light* is felt on an individual level but incorporates a cosmic understanding of the interconnectedness of all of life. Moreover, this dimension of the experience of hope seems to both transcend and envelop past, present, and future.

I respond to the simplicity of this panel, often reflecting on the importance of the little things in life and the times when I have felt fully in harmony with the world and myself. I have reflected upon my own experiences of perfect peace. The strong presence of religious relics in this foundation square draws attention to the centrality of Christianity as part of Vanessa's, Christa's and Grace's experiences of hope—and my own. Even Anna named the cross as an image of hope despite her disaffection with organized religion.

The items are different than those depicted in Christa's panel, described earlier, in which the items are oriented to the present. The items in this square depict relics, which incite memories of Grace's grandmother. While looking at the items in this panel I have been reminded of my own memories—events, experiences and people from my past who have taught me about hope, and all that has contributed to the foundation of my own hope.

<u>Revisiting The Literature</u>

Because hope is most frequently associated with 'expectation', 'anticipation',

'probabilities' and 'goal attainment', the most common theme permeating the hope literature is that of hope's 'future orientation'. Stotland's (1969) oft-quoted assertion stands as the most blatant example: "hope is the expectation greater than zero of achieving a goal" (p. 2). Stotland notwithstanding, the majority of definitions of hope maintain that (at least) one dimension of hope and the hoping process is a future orientation (Cutcliffe, 1997; Hall, 1990; Hinds, 1984; 1988; Snyder, 1994; Stanley, 1978). Synthesising definitions gleaned from hope literature, McGee (1984) stated, "hope is futuristic, motivating, involves expectancy and is action oriented" (p. 35). Other researchers have allowed for a more fluid, contextual and integrative exploration of the relationship between time and hope. Jevne (1991) for example, presents hope in the *context* of time: "Hope is always set in the context of time. It draws on the past, is experienced in the present and is aimed at the future" (p. 150). Christian theologian Jacques Ellul (1977) said it this way:

> Hope already implies an extra-temporal relation, for it is the meeting place of the future with eternity ... hope causes this future-eternity relation to intervene in the present instant *and* in the current event. Hope, then, is that which establishes the right relation between a future (other than a succession of moments) and a present . . .[consequently] we must affirm that hope has the effect of structuring time, of giving it both a value and a continuity. (p. 231-232)

Weavings

Reflecting upon the conversations with the participants, I recognize that I have heard varying assertions regarding hope and time—many of which confirmed prior research findings. Christa, for example, repeatedly spoke of goals (for herself and her child) in relation to hope and had her eye set on the future. Similarly, Vanessa had set for herself the goal of living to see her youngest child graduate from High school. In fact all five of the participants' experiences embodied 'anticipation'; reflecting anticipatory or future-oriented hope. Additionally, the

dynamic interaction between the past, present, and future could also be overheard in their experiences of hope. Anna's experiences stand as the most vivid example of this: *There's no place like home* coupled with *Somewhere over the rainbow*. Grace lives with the memories of her grandmother, a source of hope. These memories are present with Grace, motivating her to act in certain loving (and hopeful) ways.

Nevertheless, the *present* experience of hope can neither be ignored nor adequately described using scientific or everyday language. I found this dimension of the experience to be not only compelling, but also understated in the scientific literature. It seems to be the poets, philosophers, and theologians rather than social scientists who provide the most adequate insight into the immediate experience of hope.

Perhaps we as researchers cannot divest *ourselves* from the future orientation so engrained in the psyche of our North American culture. To truly explicate *Hope: The Present Light* one might turn instead to the writings of the mystics or to those writings that describe experiences of meditation, prayer, yoga, or Tai Chi. Even the most astutely written research endeavours to date have not been able to fully capture the essence of the harmonious experience of peace represented by this theme. This may be better left to the arts: poetry, music, painting, and photography. In the moment one feels hope, the past and future do not enter into consideration; it is a visceral experience, encompassing one's entire being. Moreover, it is experienced in a way that transcends time.

Hope: The Present Light might be explored using the following questions as a guide. How is hope experienced in time and beyond time and/or outside of time? How does HIV/AIDS alter one's perception of time? How does the experience of hope/hoping alter one's perception of time? What is the experience of hope in the context of relaxation, meditation, or living in the moment?

The Braided Streams

Along with conveying the participant's experiences of hope, the quilt portrays the three theoretical perspectives interwoven throughout the project and introduced in Chapter Three of this study. The intertwined aspects of feminism, human ecology and phenomenology are represented on the quilt by three overlapping almost braided pieces of fabric running lengthwise on either side of the quilt. The braided pieces are blue-green segments of fabric positioned on the rich, deep purple border of the quilt. These braided pieces represent the rootedness and fluidity which characterize the three modes of thought.

In the following sections, the three streams are revisited and examined in relation to this study. Under the heading "weavings" suggestions for further exploration of hope in the context of HIV/AIDS are offered based upon these theoretical perspectives.

Feminism

The word feminism was never used during my conversations with the women of this study. Each of the women however, experienced the effects of sexism and functioned within the realities of systemically entrenched imbalances of power—many of which are gender-based. Moreover, each of the women's circumstances underscored longstanding social issues related to gender such as poverty and health care. In the participants' stories we heard of violence at the hands of boyfriends and partners, struggles with decisions regarding childbirth, the sense of being discounted by physicians regarding women's health concerns, and uncertainty about medical treatments or medications which had not been adequately tested among women. Paralleling this were concerns encompassing the areas of care-giving and mothering, sexuality and body-image. In short, the three dimensions of feminism highlighted in Chapter Three (gender, difference, and the imperative for social change) were intertwined components of the lived-experience of these five women.

As stated at the outset of this chapter, the incorporation of some form of art was an important dimension of this project. The fact that a quilt emerged illustrates the woman-centeredness of the research. Traditionally, quilting has been women's work: a form (sometimes the only form) of personal expression and a way of recording women's personal histories. This quilt represents the individual uniqueness of five different women and their personal experiences of hope. A woman researcher worked with a woman artist to interpret the research and create the quilt. Mary and I did this co-operatively, in dialogue and sharing (usually over food). One of our meetings took place in a quaint Victorian tea parlour! I insisted that the dominant colour on the quilt be purple, the colour associated with both spirituality and feminism.

Human Ecology

Human ecology offers a perspective from which to consider the personal environments of individuals, the social, political, cultural, economic and physical contexts in which individuals thrive, and the relationships between people and their varied domains. Having already discussed the issues of gender intertwined with the participants' experiences of hope, within each woman's experience we also recognize the contextual. This includes their interactions within and between the environments of family, work, school, the law, and the medical establishment as well as their confrontations with the realities of poverty, race, social customs, and values. All of these have had a bearing on the individual experiences of hope.

Within each of the women's experiences of hope we recognize the contextual. For instance, Anna's experience of hope embodied the context of HIV discrimination and the shock of both her brother and father's death. Grace's experience of hope was linked with an automobile accident and dependent upon the technologies that saved her life. The contextual emphasis confirms that Christa's experience of hope would have been wholly different without her child. Likewise, Chantal's experience of hope would have been different had she not lived in fear of abuse. Because of her previous battle to overcome addiction, her struggles with poverty and the

need to force her physician to take notice of her ailments, Vanessa equated strength with hope when describing her experience.

Understanding the interrelated character of these personal and social interactions is at the heart of the ecological perspective. The women's experiences included interactions with family and friends, co-workers, healthcare professionals, religious institutions, work and school. The interactions were both positive and negative in scope and have had a bearing on each person's hope. For example, Chantal was apprehensive about disclosing her HIV status to both her mother and sister; consequently she felt alone, with no support and (thus) felt *too tired to hope.*

The quilt itself is contextual, created by two women at a specific time and under specific circumstances while each panel represents the particular context of each participant's experience of hope. On each panel of the quilt there is a red AIDS ribbon, to signify that the context of this research is HIV/AIDS. The presence of the five red ribbons in each of the foundation squares further signifies the centrality of HIV/AIDS in the lives of the women and the way HIV/AIDS has altered and permeated the context of each woman's life.

Phenomenology

At the heart of phenomenological philosophy and research is the affirmation of human "situatedness" in the world. In other words, phenomenology always begins in the life-world and asserts that experience is inextricable from historical-cultural context and intersubjective, constituted meaning: "...We might say that hermeneutic phenomenology is a philosophy of the personal, the individual, which we pursue against the background of an understanding of the evasive character of the *logos* of *other*, the *whole*, the *communal*, or the *social"* (van Manen, 1994, p. 7).

This hermeneutic phenomenological inquiry was based on the description of five women's personal experiences of hope. Prolonged reflection upon those experiences and descriptions led to a deeper understanding of the experience. That is, by highlighting five threads

common to their personal experiences, a mutual, shared meaning was brought to light. In this way the personal, subjective experiences of the five participants became the stepping stones for a more expansive understanding of the phenomenon of hope.

From the standpoint of hermeneutic phenomenology, the self-defining and self-interpreting nature of human beings describes both the process and capacity for human 'understanding' and the very nature of our "Be-ing". With its focus on the taken-for-granted world of everyday life, phenomenology offers a perspective and 'methods' for exploration of human *experience*, in this case, the experience of hope. With its twofold focus of description and interpretation *(what is the experience like and what does it mean?)* hermeneutic phenomenology challenges claims to objectivity and instead places the researcher squarely within the ongoing dialogue and process of meaning-making. Thus, hermeneutic phenomenology is a highly personal, embodied activity encompassing both a moral dimension and an element of caring. Van Manen (1994) puts it this way:

> To do [phenomenological] research is always to question the way we experience the world, to want to know the world in which we live as human beings. And since to *know* the world is profoundly to *be* in the world in a certain way, the act of researching—questioning—theorizing is the intentional act of attaching ourselves to the world, to become more fully part of it. (p. 5)

Far from being clinical in tone, phenomenology seeks to elicit feeling and call forth meaning where it is often taken for granted. In this sense, phenomenology is an art, as one interacts with art and responds to it both affectively and cognitively. Because the quilt elicits a response and demands interpretation, it is another form of phenomenology. Each person who looks at the quilt responds to it in certain ways. At one glance we respond to an image that resonates as true to our experience, while at another point we are given reason to reflect more

deeply. Like a quilt, phenomenology too is made up of many parts, each part relating to the whole (van Manen, 1994).

Weavings

Recently a proliferation of literature has emerged regarding women and HIV/AIDS. The fact that the literature did not emerge until well into the epidemic accentuates one of the issues at the core of gender inequality: the minimizing of women's experience. In spite of the renewed interest in the research of hope, especially within the helping professions, there is an obvious deficiency in research addressing gender differences in the experience of hope/hoping.

The characteristics associated with human ecology (context, relationships, interactions and outcomes) and its cross-disciplinary applicability make it appropriate to the study of hope among women living with HIV/AIDS. In spite of the fact that hope research spans the disciplines, the majority of hope research has tended to focus on *individual* characteristics, with context considered only peripherally. A human ecological perspective affirms that hope is determined by multiple contexts and varying interactions. The human ecological framework can stimulate investigators to look beyond merely identifying individual characteristics, to instead study the *relatedness* of variables, the interrelatedness of variables and the dynamic processes that deplete or engender hope.

As a descriptive endeavour, phenomenology rejects the impulse to quantify, define, or make specific those experiences or concepts that make up our everyday world. Seeking instead to illuminate understandings about the experience, the process of interpretation is not undertaken in a removed way as one would dispassionately study an object, but is necessitated by "the fundamentally anxious mode of being...that is continually striving for meaning" (Grondin, 1994, p. 34). Certainly HIV/AIDS presents a situation where hope can both provide and inspire meaning. But rather than simplify the concept of hope, phenomenological explorations can widen

our understanding of its experiential realities by revealing the *variety* of possible meanings embodied in one experience.

Hope is by no means a tidy concept. There are no sharp boundaries between hope and other concepts such as love, faith, or trust. Each of the three frameworks offers a particular perspective on the complexity of the topic; and can offer unique slant on the study of hope. However, continued explorations integrating the three perspectives offers potential for hope research among those who live with HIV/AIDS;
indeed, without losing the complexity, but embracing it. Interpretive investigations could address the following questions:

- What is the experience of hope among women of varying race, age, class, sexualities, cultural, educational or religious backgrounds?
- What are the effects of poverty, sexism, AIDS prejudice, or other forms of oppression on women's experiences of hope?
- What is the experience of hope among women with HIV/AIDS who identify with a particular group identity (cultural, ethnic, or sexual)?
- What are the experiences of hope at critical junctures in the progression of HIV disease (upon initial diagnosis; a drop in t-cell count or increase in viral load; decisions regarding pregnancy; at the birth of child; at the death of a child, partner or friend; diagnosis of AIDS or onset of symptoms)?
- What kinds of environments foster or engender hope among women with HIV/AIDS? What kinds of relationships? What kinds of interactions?
- What is the experience of hope when dealing with male (vs.) female physicians? Counsellors? Pastors? Nurses? Friends? Family members?
- What metaphors do women use to describe the immediate experience of hope? What kinds of words or images are utilized?

The Four Corners

In each of the four corners of the quilt is a small square depicting one of the four seasons: winter, spring, summer and fall. These are simple depictions: the same rolling hill scene during each of the four seasons of the year. Four is the number of wholeness: the four points on the medicine wheel; the four directions of the wind (east south, west and north); the four dimensions of human wholeness (mind, heart, spirit, and body); the four elements of creation (air, earth, fire, and water); and the four seasons (winter, spring, summer, and fall).

The four corners represent the passage of time and the flowing of the seasons. When I look at these four pictures, I think about the time that has passed since this project began and how important time is to each of the participants. I also think about how illness, accident, or hardship can drastically change our concept of time and how 'time' encompasses all of us, in circularity, in continuance and hope.

Most of the hope research portrays a western, linear understanding of time. Namely, that time somehow moves forward toward "the future". Acknowledging this, I also I wonder about the experience of hope – my own moments of hope, which more often than not come when I most deeply recognize myself as part of the cyclical wholeness of life, rather than within a particular time orientation.

Time is also significant to HIV/AIDS. The historical context of the unfolding epidemic, the race to contain and find a cure for AIDS, and the importance of time to individuals living with HIV/AIDS are just some of the considerations related to time.

The four corners represent the time-bound character of this research: my prior understandings and history with individuals and within the context of HIV/AIDS in the U.S.; the current context of HIV/AIDS; and the current perspectives I bring to the project. My own interpretation of the material is indeed time-bound; in the next cycle of seasons, I would have written something very different from that which has been written now.

Perfection, Quilts and Hermeneutics

Although complete and beautiful, the quilt is not perfect. Actually there are a number of changes I would make were I to have the chance to start anew. For example, the sun depicted on the quilt would be softer and more flowing, less rigid in the way it brings the five panels together. I have looked at the rays of the sun pointing upwards and thought, "the sun is incomplete; it's not symmetrical!" The sun's rays would point downward as well as upward for wholeness, to demonstrate that hope is both inwardly felt and outwardly experienced, and to illustrate that hope is linked to our past experiences but radiates in a way that pulls time (past, present and future) into the whole. I've wanted synchronicity, and harmony. At the same time, I realize that hope's true nature is not to be tamed. Hope is not always what we want it to be. At times it can be motivating, inspiring or renewing while at other times it may be comforting or challenging.

Similar to the quilt, this project is not perfect. There are things I would do differently were I to begin again. Mainly, I would have conducted the interviews in a way that brought the participants together, perhaps conducting the conversational part of the research in the context of a retreat, where the individual voices could also be blended together. It would have been enlightening to hear the women's conversations with each other—agreeing and disagreeing—comparing and contrasting their experiences of hope. Additionally, in the context of a retreat or in community, experiences of hope might be engendered, which could then be explored in a more immediate way.

Secondly, I would have allowed the photography to take a more central place in the project. The conversations around the photos were critical additions to the richness of the women's descriptions of their experiences of hope. The cameras themselves were of poor quality and none of the participants had much experience with photography. Providing better cameras might have added to the quality of the photos, making it possible to incorporate the photos themselves into the text of the thesis, rather than relying on my verbal descriptions of them.

Because of the poor quality of the photos, and my concerns about confidentiality, I chose not to include the participants' photos. I believe now that being able to add the specific photos would have made the project different, and better.

Although providing additional insights to two of the participant's experiences of hope, the journals overall were a disappointment. I would, however, change this aspect of data collection to make it easier and more appealing for the participants. In this study I provided the participants with blank journals and an open-ended invitation to write about their experiences of hope. If replicating this study, I would provide an altogether different kind of journal, with an assortment of specific questions for written reflection, stories and/or pictures inviting written responses, blank pages for drawing or pasting pictures of their own choosing. In this way the journals would be both more focused and potentially more appealing to the participants by providing options for entries.

Because this project involved three consecutive trips to Pennsylvania, some of the logistics were problematic. Scheduling three trips to Pennsylvania meant that six schedules (the five participants, and mine) would have to mesh during a particular and limited period of time. Although arrangements were made prior to each trip, participant illness, their work schedules and travels occasionally made it difficult to keep the appointments within my time constraints. Because of a change in physician appointment, one conversation took place at a playground near the physician's office, which was more convenient for the participant that day than meeting in her home. Another conversation took place in my vehicle outside of the hospital where one participant was spending the day undergoing a rescheduled round of tests. Conducting the research over a two or three-week time span may have alleviated some of the logistical difficulties. However, the richness gleaned from the prolonged research time would have been lost. Scheduling the three trips over the course of six months allowed for changes in perspective and life's events, which contributed significantly to the project.

Looking at the quilt and pondering what changes I would make, I have thought about the nature of interpretation at the heart of a project such as this. The project may be complete but it is never perfect; it invites reaction, evaluation and response. In this sense it is offered as part of the ongoing conversation about the meaning of hope.

Conclusion

This exploration has confirmed a number of important issues in relation to the experience of hope. Foremost is the affirmation of the experience of hope within the context of HIV/AIDS. This exploration has also confirmed that the experience of hope is made up of many components, some of which may be uniquely configured within each individual while at the same time being common to others. Thus this exploration has revealed the nuances of meaning that are particular to the five individual women while revealing themes comprising more universal characteristics of the phenomenon. This exploration has also confirmed the relational qualities at the core of the experience of hope. Within each woman's panel of the quilt is embroidered a tiny forget-me-not. I will not forget these five women; nor will I forget what they have shared with me and taught me about hope as their experiences have now become part of my own experience(s) of hope.

At the core of HIV/AIDS in the United States is paradox. On the one hand, along with the devastating physical realities of AIDS, its history is characterized by neglect of individuals, homophobia, desanctification of human beings and that which is destructive to the human soul and spirit. Juxtaposed with these however, are the stories of healing, transformation, a sense of community, political change and rediscovery of the sacred as a consequence of HIV/AIDS. Another paradox is this: in the midst of death, despair and meaninglessness can be found the life-affirming experiences of pride, meaning, and hope. Thus the experience of hope in the midst of HIV/AIDS is no oxymoron, though it may be another paradox holding profound meaning and promise! Susan Sontag (1988) asserts, "The generic rebuke to life and to hope is AIDS" (p.24). But the experiences of hope which Chantal, Grace, Vanessa, Anna and Christa have uncovered

convey *another* truth, which stands in creative, paradoxical tension with Sontag's tragic assertion. Namely, the universal rebuke to death, and to AIDS is the experience of hope!

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AIDS SERVICES CENTER

60 WEST BROAD STREET, SUITE 205
BETHLEHEM, PA 18018-5721
610/974-8701
FAX 610/974-8703

Letter of Agreement

This is to serve as an initial letter of agreement between the AIDS Services Center, Inc. and Carol Vogler.

Carol Vogler wishes to work with the AIDS Services Center to further her doctoral research in the area of Human Ecology and Educational Psychology. Specifically, she wishes to interview a small number of women clients regarding their experiences of hope in the midst of HIV infection and AIDS.

To this end Ms. Vogler requests the ability to recruit, meet with and interview clients. Prior to doing so, it is recognized that every potential participant would provide written informed consent, and would have the ability to withdraw that consent at any time for any reason. Current ASC Case Managers would be consulted by Ms. Vogler for their insights and expertise regarding the research.

It will be the responsibility of Ms. Vogler to comply with all laws and restrictions regarding confidentiality of client data. Ms. Vogler will also comply with all federal regulations of both the United States and Canada regarding research with human subjects. A copy of the policies of the University of Alberta regarding research with human subjects will be provided to ASC. There will be no financial costs to ASC regarding this project.

This is an initial agreement, pending approval of the research proposal by the University of Alberta and funding of the project. A more formal agreement spelling out the specifics of the research (timelines, methodology, interview questions etc.) will be drawn up prior to the beginning of the project.

Carol J Vogler
Carol Vogler

Dr. Paul D. Kyle
ASC Exec. Dir

We look forward to working with Carol on this project.

VOLUNTEERS FOR RESEARCH PROJECT: HOPE AND WOMEN WITH HIV/AIDS

Volunteers are needed to be a part of a research project on HOPE taking place over the next four months through the AIDS Services Center.

The coordinator of the project is an AIDS activist and former case manager sensitive to the issues of women living with HIV/AIDS. She will do her best to make this a safe and fun project for you to become involved with.

The intent is to study the meaning of "hope" with a small group of HIV positive women. Through conversations, photography and journals, you will be asked to talk about your experience of hope and what hope means to you in your day-to-day living. All materials will be supplied -- this will not cost you anything!

If selected, you will be asked to participate in four conversations with one person (the one doing the research)about your experience of hope while living with HIV/AIDS and to meet twice with the others involved in the project to discuss hope. You will have the right to opt out of any of the activities and to drop out of the project at anytime without explanation.

Confidentiality will be expected among the participants, and your participation in the project will not affect the use of services at ASC.

There is no formal compensation for participating in the project but it may prove to be personally meaningful to you!

IF YOU ARE INTERESTED, PLEASE SPEAK WITH YOUR CASE MANAGER OR PHONE 868-3020

Informed Consent

Research Title: An Exploration of Hope Among Women With HIV/AIDS

Note to Researcher and to Participant: *This form is to be read out loud to the participants with a witness present. After each statement is read and fully understood by the participant, the participant's initials will be placed next to each number.*

Purpose of the Study: The purpose of this study is to find out what the experience of hope is like for women living with HIV/AIDS. Through individual and group conversations with participants, the researcher expects to better understand the experience and meaning of hope.

I UNDERSTAND THE FOLLOWING:

1. _____I will meet with the researcher to talk about hope at least three times (but possibly more) over the next five months at a time and place that is acceptable to me.

2. _____I will have the option of participating in group discussions with the other participants.

3. _____My conversations with the researcher and the group discussions will be tape-recorded and then typed out (transcribed).

4. _____The researcher understands that I may not want to talk about some aspects of my experience. I can refuse to answer any question at any time without explanation.

5. _____ No one will be able to match my name to what I say. My name will not be used in reports of the study, and all personal information, tapes and typed material will be kept locked up by the researcher. This consent form with my name on it will be kept in a place separate from the other material.

6. _____I will not gain anything directly from being in this study.

7. _____Discussing my experience of hope may heighten or change my awareness of this experience.

8. _____This research study, including what I say, may be published.

9. _____What I say may be used in a different study, provided the study is approved by an ethics committee.

10. _____I may ask the researcher any questions before agreeing to be in this study. If I have more questions I can call the researcher or her supervisor at the telephone numbers listed on this form.

11._____My use of the services at ASC will not be affected in any way by my participation in this study.

12. _____I will be provided with a summary of this project and will be able to access the final results

13._____I can drop out of the study at any time without explanation.

14. _____I will receive a copy of this agreement.

15 ._____The tapes will be destroyed at the conclusion of this project.

16. _____I will be asked to take pictures representing hope. The pictures will be my property and my participation in this part of the project is optional.

Do you have any other questions or concerns at this time? _____yes _____no

_____	_____	_____
Date	Signature of Participant	Witness

If I have any questions or concerns I will phone (403) 487-4676 (collect)

HANDOUT FOR THE LITERARY WISE ONES

Participant #1
"Anna"

Anna knew nothing about HIV and was completely caught off guard by her diagnosis. Prior to her diagnosis of HIV infection (which was discovered while trying to donate blood) her life had been happy and light. She came from a close-knit family, loved to laugh and party with her friends.

Along with general malaise and some side-effects from HIV medications, Anna has experienced a number of major losses since her diagnosis. Both her father and her brother died unexpectedly and she has had to quit work to help her mother run the family business.

Hope is neither a reality in Anna's life nor is it something easily grasped. In fact, she finds hope "confusing", "complicated" and difficult to talk about. When she does talk about hope, Anna can only equate hope with "the way things used to be". Her life is defined by "before" and "after" HIV/AIDS. She remembers life before her diagnosis as having been "normal" and happy: when she used to laugh and "didn't have a care in the world". After HIV (and the other losses) life has become burdensome for Anna -- she is often depressed, with no handle on what the future might bring. Although she claims that "everyday is hopeless", she does experience moments of happiness with friends and her nieces and nephews.

There is a yearning in her description of the experience of hope: a yearning for the past and a yearning for what "could be". Anna talks wistfully about a possible cure for HIV, whenever asked about hope: "I keep thinking that maybe someday there will be a cure. . .that's what I hope for, that it's right around the corner. . .someday there will be an end to this and all the sick people will leave the hospital smiling"

I asked her to describe for me a picture of hope. Anna described an image of mountain peaks surrounded by blue sky and puffy clouds. She says that this image depicts for her where her father is and where she hopes to be after she dies.

HANDOUT FOR THE LITERARY WISE ONES

Participant #1
"Anna"

Please give as much information as possible, citing an author, title and/or page number of the scene (or xerox a copy of the page). The more information you can provide for me, the better!

Describe a scene from a book (fiction or non-fiction) or a story which depicts Anna's situation or Anna's yearning hope. Perhaps a character best depicts the yearning I have described. . .

Is there a movie, or scene from a movie, which for you depicts Anna's yearning hope for things to be the way they "used to be"?

Do you know of any poems that convey or portray what I have described of Anna?

Is there a piece of commonly known music (with or without words) which reminds you of Anna's yearning hope?